AMERICAN ACADEMY OF PEDIATRICS

Textbook of Pediatric Care

2nd EDITION

McInerny

ADAM ✻ CAMPBELL ✻ DeWITT ✻ FOY ✻ KAMAT

American Academy of Pediatrics

DEDICATED TO THE HEALTH OF ALL CHILDREN®

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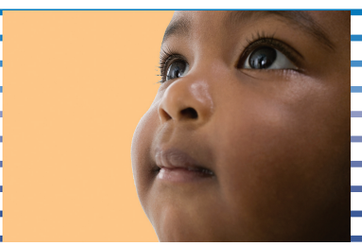

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Every effort is made to keep this publication consistent with the most recent advice and information available from the American Academy of Pediatrics.

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Dedication

We dedicate this edition to Robert Hoekelman, MD, whose legacy of excellence, commitment to quality health care for children, and dedication to education in pediatrics are reflected in these pages.

Foreword

The American Academy of Pediatrics (AAP) and our member pediatricians dedicate ourselves to promoting the optimal physical, mental, and social health and well-being of infants, children, adolescents, and young adults. An important aspect of our work is creating the educational materials necessary to provide appropriate, equitable, and high-quality pediatric care. I am proud to announce the second edition of the *AAP Textbook of Pediatric Care*.

The AAP is the leading publisher in the field of pediatrics, offering more than 500 publications, both print and electronic, for pediatricians and other health professionals who care for children. This kind of leadership saves lives, improves children's health, and supports the high quality of the profession of pediatrics.

The second edition of the *AAP Textbook of Pediatric Care* was created by a distinguished editorial team led by Thomas K. McInerny, MD, FAAP. Featuring contributions from experienced clinicians worldwide, this textbook addresses clinical issues faced by physicians who care for children: screening, diagnosis, treatment, and management for both common and uncommon diseases. The second edition contains more than 75 new chapters on specific diseases, conditions, signs, symptoms, and more. Priorities for the 21st century, including the practice of evidence-based medicine, electronic health records, and continuous quality improvement, are also addressed. There is fully integrated coverage of mental health topics, in keeping with the Academy's mission, and enhanced discussion of the family-centered medical home, including important topics such as health literacy.

Because the practice of pediatrics is constantly changing and because we need information to be accessible in multiple ways, we also offer this textbook as part of *Pediatric Care Online,* our Web-based point-of-care resource. *Pediatric Care Online* was brand new when the first edition of this textbook was published. It has since grown into an indispensable and comprehensive resource for the practicing pediatrician. It features the complete text of this book and the *Red Book*, an extensive library of patient education handouts in English and Spanish, quick reference topics based on this book, interactive clinical tools, and much more. Please see pediatriccare.solutions.aap.org for updates to the *Textbook* and the latest news in pediatric health care.

Benard P. Dreyer, MD, FAAP
President, American Academy of Pediatrics, 2016

Introduction

In 2008, the American Academy of Pediatrics (AAP) revised and updated Dr. Robert Hoekelman's venerable *Primary Pediatric Care* to create a new, comprehensive resource centered around the concept of the medical home. The first edition of the *AAP Textbook of Pediatric Care* applied the principles of evidence-based medicine to a diverse range of practice settings, including community health clinics, solo and private group practices, and hospitals, and to pediatricians practicing in urban, suburban, and rural areas.

The nearly eight years since that first publication have seen enormous changes in the practice of pediatric medicine; in our understanding of the relationships between mental and physiologic health and between early childhood adversity and long-term health outcomes; and, not the least, in the ways in which medical information can be organized, distributed, and accessed. This new, fully revised second edition has been created in response to these important challenges.

Reflecting the importance of incorporating mental health care into routine primary pediatric care, we have reorganized the book's content so that mental health screening, surveillance, promotion, symptoms, and conditions are now fully integrated throughout, rather than being divided into a separate section. New chapters have been added, including several based directly on the work of the AAP Task Force on Mental Health.

In addition to the enhanced coverage of mental health topics, new chapters have been developed that cover more than 25 new diseases and conditions and more than a dozen new signs and symptoms. Furthermore, each chapter's selection of Tools for Practice has been fully updated. Two dedicated tools editors have undertaken the task of reviewing and curating these tools for patient engagement, medical decision support, community advocacy, and practice management throughout the book.

The AAP recognizes that physicians need not only in-depth educational and resource materials for learning but also point-of-care decision support and tools to engage patients. To meet these needs, the *Textbook* is now seamlessly integrated within *Pediatric Care Online*, the essential AAP resource for trusted pediatric information. The *Textbook*, linked with the other components of *Pediatric Care Online*—namely, *Red Book Online* and *Pediatric Patient Education*—provides a single point-of-care resource for child health professionals as we continue to move into an increasingly digital world. In addition, *Pediatric Care Online* provides a more-than-complete version of the *Textbook*, including full reference lists, interactive tools and forms, new and updated Point-of-Care Quick Reference topics, and exclusive online-only chapters, beginning with an important chapter on Disaster Preparedness and Response, which is available now.

In addition to these exciting electronic developments, we think you will find the core content of the *Textbook* more valuable and relevant than ever.

Part 1, **Delivering Pediatric Health Care**, discusses health care delivery and organizational issues for pediatric practices, including the use of electronic health records, digital resources, evidence-based medicine, and methodologies for quality improvement. This new edition highlights the importance of patient- and family-centered care.

Part 2, **Principles of Care**, has been reorganized to encompass the full range of traditional pediatric practice as well as emerging issues that pediatricians now deal with day to day. Section One covers physical, behavioral, and social assessment. Section Two features a greatly expanded discussion of health promotion based on the *Bright Futures* guidelines, including environmental health, community pediatrics, surveillance and screening, and, crucially, emerging issues such as obesity, physical activity, healthy use of media, and violence prevention. Section Three covers the general management of children with health and behavioral problems, including communication strategies, the provision of culturally effective care, pain management, psychosocial and psychopharmacologic therapies, transitions to adulthood, and palliative, end-of-life, and bereavement care. Section Four highlights the unique challenges to the pediatrician in caring for special populations, such as children exposed to adverse childhood experiences, in foster or kinship care, in the juvenile justice system, and in military families, as well as lesbian, gay, and bisexual youth.

Part 3, **Maternal and Fetal Health: Effect on Pregnancy Outcomes and Perinatal Health**, discusses the developing opportunities in prenatal diagnosis and fetal interventions as well as perinatal preventive care, assisted reproductive technologies, and the effects of maternal depression.

Part 4, **Care of Healthy and High-Risk Infants**, covers the primary care pediatrician's role in neonatal care. Section One addresses routine care issues, such as breastfeeding, the circumcision decision, hospital discharge, and follow-up care, as well as medical-legal considerations. Section Two deals with assessment and physical examination of the newborn, including maternal medical history, common congenital anomalies, and postnatal evaluation of prenatal findings. Section Three covers the most common neonatal medical conditions, including jaundice, abnormalities of growth, breathing disorders, heart murmur, cyanosis, metabolic conditions, and neurologic findings. Section Four provides guidance in caring for the high-risk infant, including surgical emergencies of the chest and abdomen. Section Five encompasses health and developmental outcomes of medically complex neonates, including very preterm and very low-birth-weight infants as well as those with significant congenital heart disease and those treated with therapeutic hypothermia. This section also discusses palliative and supportive care needs. Section Six provides guidance on supporting families whose infant is sick or dying.

Part 5, **Adolescence**, discusses issues specific to teenagers, such as interviewing and counseling, as well as adolescent sexuality, including contraception, pregnancy, and abortion.

Part 6, **Presenting Signs and Symptoms**, provides alphabetized, easy-to-use guidance on 85 of the most common physiologic and behavioral signs and symptoms encountered by the pediatrician. These chapters include the physical and laboratory evaluation necessary to formulate a differential diagnosis, followed by approaches to initial management and guidance on when to refer and when to admit.

Part 7, **Specific Clinical Problems**, details the common physical and mental health issues seen in pediatric primary care settings. The latest evidence-based medicine information is used to enable the pediatrician to follow the recommended guidelines for diagnosis and treatment.

Part 8, **Critical Situations**, guides the pediatrician in responding to life-threatening illnesses and injuries seen in children, including psychiatric emergencies such as suicidality and psychosis, enabling rapid diagnosis and treatment.

As always, this textbook marshals the full resources and expertise of the AAP. The contributing authors include more than 500 top clinicians and experts across the scope of pediatrics and children's health. Each chapter has been reviewed by experts representing the relevant AAP committees, sections, and councils to ensure that the best evidence and AAP policy are reflected. Finally, chapters are cross-referenced to relevant AAP policy statements, clinical and technical reports, and clinical practice guidelines.

We would like to gratefully acknowledge the work of the AAP editorial team, including senior developmental editor Chris Wiberg and assistant editor Carrie Peters, along with the many other staff members from AAP Publishing who have made this new edition possible. We hope you will find this textbook to be a valuable addition to your library—in print, digital, or both formats—and an indispensable resource as you care for your patients.

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116: *Health and Developmental Outcomes of Selected Medically Complex Neonates*

Jayanthi Chandar, MD
Associate Professor of Clinical Pediatrics
University of Miami Miller School of Medicine
Medical Director, Pediatric Kidney Transplant Program
Miami Transplant Institute
Miami, Florida
163: *High Blood Pressure*

Pimpanada Chearskul, MD, FAAP
Children's Hospital of Michigan
Department of Pediatrics
Wayne State University School of Medicine
Detroit, Michigan
308: *Parasitic Infections*

Amy Yuntzu-Yen Chen, MD, FAAD
Assistant Professor of Dermatology
Department of Dermatology
University of Connecticut School of Medicine
Farmington, Connecticut
95: *Neonatal Skin*

Catherine Chen, MD
Division of Dermatology
Scripps Clinic Medical Group
San Diego, California
209: *Acne*
345: *Verrucae (Warts)*

Meera Chitlur, MD
Barnhart Lusher Hemostasis Research Endowed Chair
Director, Hemophilia Treatment Center and Hemostasis Program
Associate Professor of Pediatrics
Wayne State University School of Medicine
Children's Hospital of Michigan
Detroit, Michigan
262: *Hemoglobinopathies and Sickle Cell Disease*

Emma Ciafaloni, MD, FAAN, FANA
Professor of Neurology and Pediatrics
University of Rochester Medical Center
Rochester, New York
293: *Muscular Dystrophy*

Melinda B. Clark, MD, FAAP
Associate Professor of Pediatrics
Division of General Pediatrics
Albany Medical College
Albany, New York
240: *Dental Problems*

Garfield Clunie, MD
Assistant Professor of Obstetrics and Gynecology
Division of Maternal-Fetal Medicine
Icahn School of Medicine at Mount Sinai
New York, New York
82: *Prenatal Diagnosis*
83: *Fetal Interventions*

Chanelle A. Coble, MD, FAAP
Assistant Professor of Pediatrics
Division of General Pediatrics/Adolescent Medicine
New York University School of Medicine
New York, New York
121: *Adolescent Sexuality*

Bruce H. Cohen, MD
Director of the NeuroDevelopmental Science Center
Professor of Pediatrics
Akron Children's Hospital
Northeast Ohio Medical University
Akron, Ohio
223: *Brain Tumors*

Judith A. Cohen, MD
Professor of Psychiatry
Allegheny General Hospital
Drexel University College of Medicine
Pittsburgh, Pennsylvania
317: *Post-traumatic Stress Disorder*

William I. Cohen, MD†
278: *Intellectual Disability*

Molly Cole
Director, CT Council on Developmental Disabilities
Past President, Family Voices Inc.
Albuquerque, New Mexico
9: *Partnering With Families in Hospital and Community Settings*

Blaise Congeni, MD
Director, Division of Infectious Diseases
Akron Children's Hospital
Akron, Ohio
60: *Antimicrobial Therapy*

Elizabeth Alvarez Connelly, MD
Assistant Professor of Dermatology
Department of Dermatology and Cutaneous Surgery
Assistant Professor
Department of Pediatrics
Co-Director of the Division of Pediatric Dermatology
University of Miami Miller School of Medicine
Miami, Florida
326: *Seborrheic Dermatitis*

Carol Conrad, MD
Director, Pediatric Lung Transplant Program
Associate Professor of Pediatrics
Stanford University
Palo Alto, California
348: *Airway Obstruction*

W. Carl Cooley, MD, FAAP
Chief Medical Officer, Crotched Mountain Foundation
Clinical Professor of Pediatrics
Geisel School of Medicine at Dartmouth College
Hanover, New Hampshire
6: *Medical Home Collaborative Care*
7: *Planned Coordinated Care to Support the Medical Home*

Lynzee A. Cornell, PhD, F-AAA, CCC-A
Clinic Director and Assistant Professor
Division of Audiology
University of Louisville School of Medicine
Louisville, Kentucky
26: *Auditory Screening*

†Deceased

Timothy Cornell, MD
Associate Professor
Director, Pediatric Critical Care Fellowship
Department of Pediatrics and Communicable Diseases
University of Michigan
Ann Arbor, Michigan
373: *Shock*
Appendix B: *Outpatient Procedures*

David N. Cornfield, MD, FAAP
Anne T. and Robert M. Bass Professor of Pulmonary Medicine
Director, Center for Excellence in Pulmonary Biology
Department of Pediatric and (by courtesy) Surgery
Stanford University School of Medicine
Chief, Pulmonary, Asthma, and Sleep Medicine and Medical Director, Respiratory Therapy
Lucile Salter Packard Children's Hospital at Stanford
Palo Alto, California
348: *Airway Obstruction*
372: *Severe Acute Asthma (Status Asthmaticus)*

Josef Misael Cortez, MD, FAAP
Assistant Professor
Division of Neonatal Perinatal Medicine
Department of Pediatrics
Wayne State University School of Medicine
Detroit, Michigan
104: *Prenatal Drug Use: Neonatal Effects and the Drug Withdrawal Syndrome*

Susan M. Coupey, MD, FAAP
Professor of Pediatrics
Chief, Division of Adolescent Medicine
Albert Einstein College of Medicine
The Children's Hospital at Montefiore
Bronx, New York
121: *Adolescent Sexuality*

Mario Cruz, MD
Assistant Professor of Pediatrics
Drexel University College of Medicine
Associate Residency Program Director
St. Christopher's Hospital for Children
Philadelphia, Pennsylvania
41: *Healthy Sexual Development and Sexuality*

Timothy P. Culbert, MD, FAAP
Medical Director: Integrative Medicine
PrairieCare Medical Group
Chaska, Minnesota
57: *Complementary and Integrative Medical Therapies*

David R. Cunningham, PhD
Professor Emeritas
Department of Surgery
School of Medicine
University of Louisville
Louisville, Kentucky
26: *Auditory Screening*

Dennis Cunningham, MD
Section of Infectious Diseases
Nationwide Children's Hospital
The Ohio State University School of Medicine
Columbus, Ohio
248: *Enterovirus and Evolving Infections*

Joseph R. Custer, MD
Pediatric Critical Care Medicine
Professor of Pediatrics and Communicable Diseases
Associate Director for Fellowship Programs
Medical Director, Respiratory Therapy Services
C.S. Mott Children's Hospital
University of Michigan Health System
Ann Arbor, Michigan
373: *Shock*
Appendix B: *Outpatient Procedures*

Lara Danziger-Isakov, MD, MPH, FAAP
Professor of Pediatrics
Director, Immunocompromised Host Infectious Disease
Cincinnati Children's Hospital Medical Center
University of Cincinnati College of Medicine
Cincinnati, Ohio
325: *Rocky Mountain Spotted Fever*

Viral A. Dave, MD, FAAP
Assistant Professor of Pediatrics
Section of Neonatology
Department of Pediatrics
Texas Children's Hospital and Baylor College of Medicine
Houston, Texas
90: *Care of the Late Preterm Infant*

Lynn F. Davidson, MD, FAAP
Assistant Professor of Pediatrics
Department of Pediatrics
Albert Einstein College of Medicine
The Children's Hospital at Montefiore
Bronx, New York
51: *Care of Children With Special Health Care Needs*

Philip W. Davidson, PhD
Professor Emeritus of Pediatrics, Environmental Medicine, and Psychiatry
University of Rochester Medical Center
School of Medicine and Dentistry
Rochester, New York
49: *Discussing Serious Symptoms, Results, and Diagnoses With the Patient and Family*

Beth Ellen Davis, MD, MPH, FAAP (COL, MC, USA, Retired)
Clinical Professor of Pediatrics
Division of Developmental Medicine
University of Washington
Seattle, Washington
77: *Children in Military Families*

Adekunle Dawodu, MBBS
Professor and Director of International Education and Patient Care
Global Health Center
Cincinnati Children's Hospital Medical Center
University of Cincinnati College of Medicine
Cincinnati, Ohio
346: *Vitamin D Inadequacy*

Lilia C. De Jesus, MD, FAAP
Clinical Assistant Professor of Pediatrics
Department of Pediatrics/Neonatology Division
UCSF Benioff Children's Hospital
San Francisco, California
104: *Prenatal Drug Use: Neonatal Effects and the Drug Withdrawal Syndrome*

Sonia Dela Cruz-Rivera, MD
Attending Pediatrician and Assistant Clinical Professor
The Children's Hospital at Montefiore
Albert Einstein College of Medicine
Division of Pediatrics
Bronx, New York
91: *Hospital Discharge of the Healthy Term and Late Preterm Infant*

Marcela Del Rio, MD, FAAP
Assistant Professor of Pediatrics
Division of Pediatric Nephrology
Medical Director, Renal Transplantation
The Children's Hospital at Montefiore
Albert Einstein College of Medicine
Bronx, New York
160: *Hematuria*

David R. DeMaso, MD
Psychiatrist-in-Chief and Chairman of Psychiatry, Boston Children's Hospital
George P. Gardner and Olga E. Monks Professor of Child Psychiatry and Professor of Pediatrics
Harvard Medical School
Boston, Massachusetts
370: *Psychiatric Emergencies: Suicidality, Agitation, Psychosis, and Disaster Exposure*

Jayant K. Deshpande, MD, MPH, FAAP
SVP/Chief Medical Officer
Arkansas Children's Hospital
Professor of Pediatrics and Anesthesiology
University of Arkansas for Medical Sciences
Little Rock, Arkansas
63: *Preoperative Assessment*
64: *Postoperative Care*

Leena Shrivastava Dev, MD, FAAP
Child Abuse Pediatrician
General Pediatrician
The Pediatric Center
Frederick, Maryland
41: *Healthy Sexual Development and Sexuality*

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University of Missouri-Kansas City School of Medicine
Division of Allergy, Asthma, and Immunology
Children's Mercy Hospital
Kansas City, Missouri
218: *Asthma*

Linda M. Dinerman, MD, PC
Adolescent and Young Adult Medicine
Private Practice
Huntsville, Alabama
141: *Dysmenorrhea*
205: *Vaginal Discharge*

Elaine A. Dinolfo, MD, MS, FAAP
Assistant Clinical Professor of Pediatrics
Columbia University
Attending Physician
Department of Pediatrics
Harlem Hospital Center
New York, New York
87: *Care of the Newborn After Delivery*
207: *Weight Loss*

Cecilia Di Pentima, MD, MPH, FAAP
Department of Pediatrics
Vanderbilt University School of Medicine
Nashville, Tennessee
60: *Antimicrobial Therapy*

Aleksandra Djukic, MD, PhD
Professor of Clinical Neurology
Director, Tri State Rett Syndrome Center
Albert Einstein College of Medicine
Bronx, New York
107: *The Newborn With Neurologic Findings*

Mary Iftner Dobbins, MD, FAAP
Department of Family and Community Medicine
Southern Illinois University School of Medicine
Carbondale, Illinois
150: *Family Dysfunction*

Eileen Dolan, MD
Department of Pediatrics
Hackensack University Medical Center
Hackensack, New Jersey
318: *Prader-Willi Syndrome*

Nienke P. Dosa, MD, MPH
Upstate Foundation Professor of Child Health Policy
Center for Development Behavior and Genetics
Department of Pediatrics
SUNY Upstate Medical University
Syracuse, New York
52: *School-Related Issues for Children With Special Health Care Needs*

Susan dosReis, PhD
Associate Professor of Pharmacy
Department of Pharmaceutical Health Services Research
University of Maryland School of Pharmacy
Baltimore, Maryland
62: *Psychotropic Medications in Primary Care Pediatrics*

Dwayne E. Dove, MD
297: *Neurocutaneous Syndromes*

M. Catherine Driscoll, MD
Professor of Clinical Pediatrics
Department of Pediatrics
Division of Hematology-Oncology
Albert Einstein College of Medicine
The Children's Hospital at Montefiore
Bronx, New York
103: *The Newborn With Hematologic Abnormalities*

George T. Drugas, MD, FACS, FAAP
Director of Surgical Quality Improvement
Pediatric General and Thoracic Surgery
Seattle Children's Hospital
University of Washington
Seattle, Washington
359: *Esophageal Caustic Injury*

Howard Dubowitz, MD, MS, FAAP
Professor of Pediatrics
University of Maryland School of Medicine
Baltimore, Maryland
367: *Physical Abuse and Neglect*

Paula M. Duncan, MD, FAAP
Professor of Pediatrics
University of Vermont College of Medicine
Burlington, Vermont
24: *Promoting the Health of Adolescents*
45: *Conducting the Health Supervision Visit*

Paul H. Dworkin, MD, FAAP
Executive Vice President for Community Child Health
Connecticut Children's Medical Center
Professor of Pediatrics
University of Connecticut School of Medicine
Hartford, Connecticut
25: *Screening: General Considerations*

Dana Michelle Hines Dykes, MD
Assistant Professor of Pediatrics
Division of Pediatric Gastroenterology, Hepatology, and Nutrition
Cincinnati Children's Hospital Medical Center
University of Cincinnati College of Medicine
Cincinnati, Ohio
276: *Inflammatory Bowel Disease*

Marian Earls, MD, FAAP
Clinical Professor of Pediatrics
University of North Carolina Medical School
Chapel Hill, North Carolina
Director of Pediatric Programs
Community Care of North Carolina
Raleigh, North Carolina
33: *Healthy Child Development*
84: *Maternal Depression*

Sarah Edwards, DO
Assistant Professor
Director of Training, Child and Adolescent Psychiatry Fellowship
Medical Director of Child and Adolescent Psychiatry Hospital Services
Division of Child and Adolescent Psychiatry
University of Maryland School of Medicine
Baltimore, Maryland
192: *Self-stimulating Behaviors*

Jerrold M. Eichner, MD, FAAP
Clinical Professor of Pediatrics
University of Washington
School of Medicine
Seattle, Washington
10: *Family-Centered Care of Hospitalized Children*

Mohammad F. El-Baba, MD
Division Chief, Pediatric Gastroenterology
Fellowship Program Director
Children's Hospital of Michigan
Wayne State University School of Medicine
Detroit, Michigan
142: *Dysphagia*

Dianne S. Elfenbein, MD, FAAP
Division Director, Adolescent Medicine
Professor of Pediatrics
St. Louis University School of Medicine
St. Louis, Missouri
122: *Adolescent Pregnancy and Parenthood*

Robin S. Everhart, PhD
Assistant Professor
Department of Psychology
Virginia Commonwealth University
Richmond, Virginia
47: *Adherence to Pediatric Health Care Recommendations*

Jonathan M. Fanaroff, MD, JD, FAAP, FCLM
Associate Professor of Pediatrics
Case Western Reserve University School of Medicine
Director, Rainbow Center for Pediatric Ethics
Co-Medical Director, Neonatal Intensive Care Unit
Rainbow Babies and Children's Hospital
Cleveland, Ohio
85: *Medical-Legal Considerations in the Care of Newborns*

Marianne E. Felice, MD, FAAP
Professor of Pediatrics and Obstetrics/Gynecology
Division of Adolescent Medicine
University of Massachusetts Medical School
Worcester, Massachusetts
122: *Adolescent Pregnancy and Parenthood*
371: *Rape*

Jon R. Felt, MD
Fellow, Pediatric Emergency Medicine
Carman and Ann Adams Department of Pediatrics
Wayne State University School of Medicine
Children's Hospital of Michigan
Detroit, Michigan
58: *Fluids, Electrolytes, and Acid-Base Composition*

Evan S. Fieldston, MD, MBA, MS, FAAP
Assistant Professor of Pediatrics
Perelman School of Medicine at the University of Pennsylvania
Medical Director of Clinical Operations
The Children's Hospital of Philadelphia
Philadelphia, Pennsylvania
1: *Health Care Delivery System*

Barbara H. Fiese, PhD
Professor and Director of the Family Resiliency Center
University of Illinois at Urbana-Champaign
Urbana, Illinois
47: *Adherence to Pediatric Health Care Recommendations*

Lisa Figueiredo, MD
Division of Pediatric Hematology/Oncology
The Children's Hospital at Montefiore
Bronx, New York
181: *Petechiae and Purpura*

Jeffrey S. Fine, MD, FACMT
Assistant Professor
Ronald O. Perelman Department of Emergency Medicine and the Department of Pediatrics
New York University School of Medicine
New York, New York
369: *Poisoning*

Martin A. Finkel, DO, FACOP, FAAP
Professor of Pediatrics
Medical Director, Institute Co-Director
Child Abuse Research Education Services (CARES) Institute
Rowan University School of Osteopathic Medicine
Stratford, New Jersey
367: *Physical Abuse and Neglect*

Howard Fischer, MD*
233: *Common Cold*

*Retired

Martin Fisher, MD, FAAP
Chief, Division of Adolescent Medicine
Cohen Children's Medical Center
Northwell Health
Professor of Pediatrics
Hofstra Northwell School of Medicine at Hofstra University
Hempstead, New York
216: *Anorexia Nervosa, Bulimia Nervosa, and Other Eating Disorders*

Leigh Anne Flore, MD, MS
Assistant Professor of Pediatrics
Division of Genetic, Genomic, and Metabolic Disorders
Detroit Medical Center
Wayne State University School of Medicine
Detroit, Michigan
250: *Fetal Alcohol Spectrum Disorders*

Glenn Flores, MD, FAAP
Distinguished Chair of Health Policy Research
Medical Research Institute
Minneapolis, Minnesota
69: *Caring for Families New to the United States*

Christopher B. Forrest, MD, PhD
Director, Center for Child Health Development
The Children's Hospital of Philadelphia
Philadelphia, Pennsylvania
1: *Health Care Delivery System*

Rene J. Forti, MD
Assistant Professor of Clinical Pediatrics
Albert Einstein College of Medicine
Attending Physician, Pediatric Emergency Medicine
The Children's Hospital at Montefiore
Bronx, New York
349: *Altered Mental Status*

Jane Meschan Foy, MD, FAAP
Professor of Pediatrics
Wake Forest School of Medicine
Winston-Salem, North Carolina
34: *Mental Health*
50: *Care of Children With Mental Health Problems*
62: *Psychotropic Medications in Primary Care Pediatrics*

Lorry R. Frankel, MD, FCCM
Chair, Department of Pediatrics
California Pacific Medical Center
Emeritus Professor of Pediatrics
Stanford University School of Medicine
San Francisco, California
356: *Drowning and Near Drowning (Submersion Injuries)*

Barbara L. Frankowski, MD, MPH, FAAP
Professor of Pediatrics
Division of Primary Care
University of Vermont Children's Hospital
Burlington, Vermont
23: *Promoting the Health of School-aged Children*
172: *Learning Difficulty*

Andrew L. Freedman, MD
Director, Pediatric Urology
Professor of Surgery
Cedars-Sinai Medical Center
Los Angeles, California
89: *The Circumcision Decision*

Karen S. Frush, MD
Professor of Pediatrics
Chief Patient Safety Officer
Duke University Health System
Durham, North Carolina
12: *Emergency Care*

Mamta Fuloria, MD, FAAP
Assistant Professor of Pediatrics
Director, Neonatology Fellowship Program
Department of Pediatrics
Division of Neonatology
The Children's Hospital at Montefiore
Albert Einstein College of Medicine
Bronx, New York
108: *Surgical Emergencies of the Chest and Abdomen in the Newborn*

Sheila Gahagan, MD, MPH, FAAP
Professor and Chief
Division of Academic General Pediatrics
University of California, San Diego
San Diego, California
298: *Obesity and Metabolic Syndrome*

Robert J. Gajarski, MD, MHSA, FACC
Professor of Pediatrics
Director, Cardiac Critical Care and Transplantation
C.S. Mott Children's Hospital
University of Michigan
Ann Arbor, Michigan
234: *Congenital and Acquired Heart Disease*

Mariam Gangat, MD
Department of Pediatrics
Division of Pediatric Endocrinology
Rutgers Robert Wood Johnson Medical School
New Brunswick, New Jersey
164: *Hirsutism, Hypertrichosis, and Precocious Sexual Hair Development*

Anna Christina Ganster, MD, FAAP
Assistant Professor of Clinical Pediatrics
Division of Neonatology at LAC/USC
Children's Hospital Los Angeles
Keck School of Medicine
University of Southern California
Los Angeles, California
108: *Surgical Emergencies of the Chest and Abdomen in the Newborn*

Andrew Garner, MD, PhD, FAAP
Clinical Professor of Pediatrics
Case Western Reserve University School of Medicine
Cleveland, Ohio
68: *Children Exposed to Adverse Childhood Experiences*

Jose M. Garza, MD
Director, Neurogastroenterology and Motility Program
Children's Healthcare of Atlanta
Children's Center for Digestive Healthcare
Atlanta, Georgia
232: *Colorectal Disorders*

John P. Gearhart, MD, FAAP, FACS, FRCS
Professor and Director of Pediatric Urology
The James Buchanan Brady Urological Institute
The Johns Hopkins Hospital
Baltimore, Maryland
272: *Hypospadias, Epispadias, and Cryptorchidism*

Gina Marie Geis, MD, FAAP
Attending Neonatologist
Associate Medical Director of the Neonatal Intensive Care Unit Floating Hospital for Children at Tufts Medical Center
Co-Chair of the Hospital Ethics Committee at Tufts Medical Center
Assistant Professor of Pediatrics
Tufts University School of Medicine
Boston, Massachusetts
111: *Care of the Sick or Premature Infant Before Transport*

Paul L. Geltman, MD, MPH, FAAP
Assistant Professor of Pediatrics
Harvard Medical School
Medical Director for Refugee and Immigrant Health
Division of Global Populations and Infectious Disease Prevention
Massachusetts Department of Public Health
Boston, Massachusetts
69: *Caring for Families New to the United States*

Welton M. Gersony, MD
Alexander S. Nadas Emeritus Professor of Pediatrics
College of Physicians and Surgeons of Columbia University
New York, New York
323: *Rheumatic Fever*

Harry L. Gewanter, MD, FAAP, FACR
Pediatric Rheumatologist
Pediatric and Adolescent Health Partners
Midlothian, Virginia
324: *Rheumatologic Diseases*

Mirko S. Gilardino, MD, MSc, FRCSC, FACS
Director, Plastic Surgery Residency Program
Associate Professor of Surgery
Division of Plastic Surgery
McGill University Health Centre
Director, Craniofacial Surgery
Montreal Children's Hospital
Montreal, Quebec, Canada
261: *Hemangiomas*

Jack Gladstein, MD, FAAP
Professor of Pediatrics and Neurology
University of Maryland School of Medicine
Baltimore, Maryland
157: *Headache*

Mary Margaret Gleason, MD, FAAP
Associate Professor
Child Psychiatry and Pediatrics
Tulane University School of Medicine
New Orleans, Louisiana
199: *Symptoms of Emotional Disturbance in Young Children*

Beatrice Goilav, MD
Assistant Professor of Pediatrics
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Division of Pediatric Nephrology
The Children's Hospital at Montefiore
Albert Einstein College of Medicine
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144: *Dysuria*

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Professor of Pediatrics
Columbia University Medical Center (CUMC)
Professor of Population and Family Health
Mailman School of Public Health, CUMC
Medical Director, School Based Health Centers
New York–Presbyterian Hospital
New York, New York
75: *Gay- and Lesbian-parented Families*
119: *Interviewing Adolescents*

Johanna Goldfarb, MD, FAAP
Pediatric Infectious Diseases
Cleveland Clinic Children's Hospital
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304: *Osteomyelitis*
328: *Septic Arthritis*

David L. Goldman, MD
Associate Professor of Pediatrics
Assistant Professor of Microbiology
The Children's Hospital at Montefiore
Albert Einstein College of Medicine
Bronx, New York
187: *Recurrent Infections*

Stuart L. Goldstein, MD, FAAP, FNKF
Director, Center for Acute Care Nephrology
Cincinnati Children's Hospital Medical Center
Professor of Pediatrics
University of Cincinnati College of Medicine
Cincinnati, Ohio
365: *Acute Kidney Injury*

Meggan Goodpasture, MD, FAAP
Assistant Professor of Pediatrics and Adolescent Medicine
Wake Forest Baptist Medical Center
Winston-Salem, North Carolina
292: *Münchausen Syndrome by Proxy: Medical Child Abuse*

Carol Lynn Greene, MD, FAAP, FACMG
Professor of Pediatrics
Director of Clinical Genetics
University of Maryland School of Medicine
Baltimore, Maryland
291: *Metabolic Disorders Beyond the Newborn Period*

Frank R. Greer, MD, FAAP
Professor of Pediatrics
University of Wisconsin School of Medicine and Public Health
Madison, Wisconsin
36: *Healthy Nutrition: Infants*
37: *Healthy Nutrition: Children*
38: *Healthy Nutrition: Adolescents*

D. Gary Griffin, MD, MPH, FAAP
Associate Clinical Professor
Florida State University College of Medicine
Tallahassee, Florida
339: *Tonsillectomy and Adenoidectomy*

James A. Grifo, MD, PhD
Professor of Obstetrics and Gynecology
New York University Langone Medical Center
New York, New York
81: *Assisted Reproductive Technologies, Multiple Births, and Pregnancy Outcomes*

Lindsey K. Grossman, MD, FAAP
Chair Emerita, Department of Pediatrics
Baystate Children's Hospital
Tufts University School of Medicine
Springfield, Massachusetts
266: *Herpes Infections*

James Guevara, MD, MPH, FAAP
Associate Professor of Pediatrics and Epidemiology
Perelman School of Medicine at the University of Pennsylvania
Attending Physician
The Children's Hospital of Philadelphia
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220: *Attention-deficit/Hyperactivity Disorder*

Lisa Hackney, MD
Clinical Assistant Professor of Pediatrics
Division of Pediatric Hematology/Oncology
Rainbow Babies and Children's Hospital
Cleveland, Ohio
225: *Cancers in Childhood*

Waseem Hafeez, MBBS, FAAP
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Albert Einstein College of Medicine
Attending Physician
Division of Pediatric Emergency Medicine
The Children's Hospital at Montefiore
Bronx, New York
169: *Irritability and Fussiness*

Joseph F. Hagan, Jr, MD, FAAP
Clinical Professor in Pediatrics
University of Vermont College of Medicine
Burlington, Vermont
45: *Conducting the Health Supervision Visit*

David Hains, MD
Associate Professor of Pediatrics
Division of Pediatric Nephrology
University of Tennessee Health Science Center
Memphis, Tennessee
30: *Use of Urinalysis and Urine Culture in Screening*

Caroline Breese Hall, MD†
175: *Lymphadenopathy*
224: *Bronchiolitis*
352: *Croup (Acute Laryngotracheobronchitis)*

William J. Hall, MD, MACP
Director, Center for Healthy Aging
Professor of Medicine
University of Rochester Medical Center
Rochester, New York
352: *Croup (Acute Laryngotracheobronchitis)*

David C. Hanson, MD
Assistant Professor
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Department of Pediatrics
University of Minnesota Masonic Children's Hospital
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147: *Extremity Pain*

Winita Hardikar, MBBS, FRACP, PhD, FAASLD
Associate Professor
Director of the Department of Gastroenterology
Royal Children's Hospital
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265: *Hepatitis*

†Deceased

William Harmon, MD
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Medical Director, Pediatric Critical Care Services
University of Virginia School of Medicine
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361: *Heart Failure*

J. Peter Harris, MD
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132: *Cardiac Arrhythmias*

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Institute for Healthy Childhood Weight
Elk Grove Village, Illinois
35: *Healthy Weight*

Jessica Hawkins, MS
1: *Health Care Delivery System*

Nicole Hayde, MD, MS
Assistant Professor of Pediatrics
Albert Einstein College of Medicine
Bronx, New York
264: *Henoch-Schönlein Purpura*

Nancy Heath, PhD
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McGill University
Montreal, Quebec, Canada
191: *Self-harm*

Elizabeth Baltus Hebert, PhD, OTR/L
Assistant Clinical Professor
Occupational Therapy
Nazareth College of Rochester
Rochester, New York
49: *Discussing Serious Symptoms, Results, and Diagnoses With the Patient and Family*

Sebastian Heersink, MD, FACS
Eye Center South
Dothan, Alabama
188: *Red Eye/Pink Eye*

Lauren Henderson, MD
Resident Physician
Department of Dermatology
Eastern Virginia Medical School
Norfolk, Virginia
245: *Drug Eruptions, Erythema Multiforme, Stevens-Johnson Syndrome*

Neil E. Herendeen, MD, FAAP
Associate Professor of Pediatrics
University of Rochester Medical Center
Rochester, New York
215: *Animal and Human Bites*
238: *Cystic and Solid Masses of the Face and Neck*

Ginette A. Hinds, MD
Assistant Professor of Dermatology
Johns Hopkins School of Medicine
Baltimore, Maryland
320: *Psoriasis*

Breena Welch Holmes, MD, FAAP
Maternal and Child Health Director
Vermont Department of Health
Burlington, Vermont
24: *Promoting the Health of Adolescents*

Charles J. Homer, MD, MPH, FAAP
Deputy Assistant Secretary for Human Services Policy
U.S. Department of Health and Human Services
Office of the Assistant Secretary for Planning and Evaluation
Washington, DC
5: *Quality Improvement in Practice*

Douglas N. Homnick, MD, MPH, FAAP
Medical Director
Kalamazoo County Health and Community Services
Kalamazoo, Michigan
Professor of Pediatrics and Human Development
Division of Pediatric Pulmonology
Michigan State University College of Human Medicine
East Lansing, Michigan
16: *Pediatric Physical Examination: Interpretation of Findings*

Robert J. Hopkin, MD, FAAP
Associate Professor of Clinical Pediatrics
Division of Human Genetics
Cincinnati Children's Hospital Medical Center
University of Cincinnati College of Medicine
Cincinnati, Ohio
313: *Pierre Robin Sequence*

Evalyn Horowitz, MD
Former Director, Juvenile Justice
Former Chief of Public Health
California Department of Corrections and Rehabilitation
Sacramento, California
73: *Children in the Juvenile Justice System*

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Associate Professor of Pediatrics and Physical Medicine and Rehabilitation
Division of Pediatric Rehabilitation Medicine
Department of Physical Medicine and Rehabilitation
School of Medicine
University of Pittsburgh
Pittsburgh, Pennsylvania
332: *Spina Bifida*

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Division of Endocrinology
Cincinnati Children's Hospital Medical Center
University of Cincinnati College of Medicine
Cincinnati, Ohio
342: *Turner Syndrome and Noonan Syndrome*

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Children's Mercy Hospital
University of Missouri-Kansas City School of Medicine
Kansas City, Missouri
20: *Immunizations*

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Bronx, New York
173: *Limp*

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Medical Director
Amerihealth New Jersey
Cranbury, New Jersey
Independence Blue Cross
Philadelphia, Pennsylvania
51: *Care of Children With Special Health Care Needs*
115: *Health and Developmental Outcomes of Very Preterm and Very Low-Birth-Weight Infants*

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Associate Professor
Departments of Microbiology/Biochemistry/Immunology and Pediatrics
Morehouse School of Medicine
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Division of Pediatric Infectious Diseases
Emory University
Atlanta, Georgia
236: *Contagious Exanthematous Diseases*

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Detroit, Michigan
360: *Head Injuries*

Brian Inouye, MD
Resident, Urology
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Durham, North Carolina
272: *Hypospadias, Epispadias, and Cryptorchidism*

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Louisiana State University Health Sciences Center
New Orleans, Louisiana
249: *Enuresis*

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Pittsburgh, Pennsylvania
266: *Herpes Infections*

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Bronx, New York
97: *Postnatal Assessment of Common Prenatal Sonographic Findings*

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280: *Kawasaki Disease*

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344: *Urinary Tract Infections*

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Detroit, Michigan
301: *Oliguria and Anuria*

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173: *Limp*

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241: *Diabetes Mellitus*

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Director, Neurogenetics/Metabolic Program
Director, Miami Genetic Laboratories
Nicklaus Children's Hospital
Miami, Florida
281: *Klinefelter Syndrome*

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University of Rochester Medical Center
Rochester, New York
72: *Children in Foster or Kinship Care*

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Harvard Medical School
Chief Executive Officer and Executive Vice President
Lahey Health, Community Network
Burlington, Massachusetts
15: *Pediatric History: Assessing Functioning and Mental Health*

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Howard University College of Medicine
Washington, DC
79: *Children in Poverty*

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Associate Professor of Pediatrics
Johns Hopkins University School of Medicine
Baltimore, Maryland
127: *Amenorrhea*
204: *Vaginal Bleeding*
205: *Vaginal Discharge*
330: *Sexually Transmitted Infections*

Brandon Johnson, MD
Assistant Professor of Ophthalmology and Visual Sciences
Albert Einstein College of Medicine
Bronx, New York
214: *Amblyopia and Strabismus*

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270: *Hyperthyroidism*

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Little Rock, Arkansas
29: *Screening for Genetic-Metabolic Diseases*

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Northwestern University
Chicago, Illinois
322: *Renal Tubular Acidosis*

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Wayne State University School of Medicine
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Detroit, Michigan
316: *Positional Deformational Plagiocephaly*
321: *Pyloric Stenosis*

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Wayne State University School of Medicine
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334: *Sports Musculoskeletal Injuries*

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Albany Medical Center
Albany, New York
59: *Blood Products and Their Uses*

Vishal Subodhbhai Kapadia, MD, FAAP
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Department of Pediatrics
Division of Neonatal Perinatal Medicine
University of Texas Southwestern Medical Center
Dallas, Texas
99: *Neonatal Jaundice*

Sebastian G. Kaplan, PhD
Associate Professor of Psychiatry
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Child and Adolescent Psychiatry Section
Wake Forest School of Medicine
Winston-Salem, North Carolina
31: *Applying Behavior Change Science*

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Children's National Medical Center
School of Medicine and Health Sciences
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193: *Short Stature*

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144: *Dysuria*

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Assistant Professor of Pediatrics
Albert Einstein College of Medicine
Bronx, New York
65: *Pediatric Rehabilitation*

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New Brunswick, New Jersey
93: *Maternal Medical History*
94: *Physical Examination of the Newborn*

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Durham, North Carolina
240: *Dental Problems*

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Division of Children's Primary Care
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Durham, North Carolina
28: *Vision Screening*

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The Ohio State University School of Medicine
Columbus, Ohio
57: *Complementary and Integrative Medical Therapies*

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University of Miami Miller School of Medicine
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219: *Atopic Dermatitis*
235: *Contact Dermatitis*

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27: *Screening for Anemia*

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Pediatric GI, Hepatology and Nutrition
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Stanford, California
Medical Director, Children's Home Pharmacy and the Nutrition Support Team
Lucile Packard Children's Hospital Stanford
Palo Alto, California
256: *Gastrointestinal Allergy*
259: *Gluten-Sensitive Enteropathy (Celiac Sprue)*

Jill Kerr, DNP, MPH
Family Nurse Practitioner (Retired)
Chapel Hill Carrboro City Schools Head Start
Carrboro, North Carolina
22: *Promoting the Health of Young Children*

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Warren Alpert School of Medicine
Brown University
Providence, Rhode Island
121: *Adolescent Sexuality*

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Birmingham, Alabama
227: *Chickenpox*

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Albert Einstein College of Medicine
Attending Physician
Division of Pediatric Emergency Medicine
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Bronx, New York
169: *Irritability and Fussiness*

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Yale University School of Medicine
New Haven, Connecticut
202: *Tics*

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Joseph M. Sanzari Children's Hospital
Hackensack University Medical Center
Hackensack, New Jersey
164: *Hirsutism, Hypertrichosis, and Precocious Sexual Hair Development*

Jonathan D. Klein, MD, MPH, FAAP
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120: *Counseling Parents of Adolescents*

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Philippart Chair and Professor of Surgery
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Children's Hospital of Michigan
Detroit, Michigan
347: *Acute Surgical Abdomen*

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Nemours Children's Specialty Care
Pensacola, Florida
339: *Tonsillectomy and Adenoidectomy*

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14: *Pediatric History: Assessing the Social Environment*

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306: *Pancreatitis*

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Division of Infectious Diseases
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Bronx, New York
102: *The Newborn at Risk for Infection*

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Bronx, New York
87: *Care of the Newborn After Delivery*

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Hospital for Children
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Thomas Jefferson University, Jefferson Medical College
Adjunct Professor
University of Delaware, Center for Bioinformatics and Computational Biology
Wilmington, Delaware
285: *Leukemias*

David J. Kolko, PhD, ABPP
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317: *Post-traumatic Stress Disorder*

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Director, Pediatric Pain Service
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55: *Managing Chronic Pain in Children*

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University of North Carolina Gillings School of Global Public Health
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22: *Promoting the Health of Young Children*

Richard E. Kreipe, MD, FAAP
Dr. Elizabeth McAnarney Professor of Pediatrics
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Department of Pediatrics
Golisano Children's Hospital
University of Rochester Medical Center
Rochester, New York
118: *Challenges of Health Care Delivery to Adolescents*

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Winthrop University Hospital
Mineola, New York
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State University of New York Stony Brook School of Medicine
Stony Brook, New York
228: *Chronic Fatigue Syndrome*
275: *Infectious Mononucleosis and Other Epstein-Barr Viral Infections*

Lakshmanan Krishnamurti, MD
Professor of Pediatrics
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Joseph Kuchenmeister/Aflac Field Force Chair
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279: *Iron-Deficiency Anemia*

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Johns Hopkins University
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185: *Puberty: Normal and Abnormal*

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Winston-Salem, North Carolina
186: *Rash*
242: *Diaper Rash*

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Child Development Center at Nationwide Children's Hospital
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221: *Autism Spectrum Disorder*

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29: *Screening for Genetic-Metabolic Diseases*

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Boston Children's Hospital
Boston, Massachusetts
105: *Transient Metabolic Disturbances in the Newborn*

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Philadelphia College of Osteopathic Medicine
Philadelphia, Pennsylvania
180: *Odor (Unusual Urine and Body)*

John D. Lantos, MD
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University of Missouri-Kansas City School of Medicine
Director, Children's Mercy Bioethics Center
Children's Mercy Hospital
Kansas City, Missouri
11: *Ethical and Legal Issues for Primary Care Physicians*

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Chair, Department of Pediatrics, Maimonides Medical Center
Vice President, Maimonides Infants and Children's Hospital of Brooklyn
Professor of Pediatrics
Albert Einstein College of Medicine
Yeshiva University
Brooklyn, New York
210: *Adjustment Disorder in Children and Adolescents*

Gitte Larsen, MD, MPH, FAAP
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Primary Children's Hospital
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University of Utah Medical Center
Salt Lake City, Utah
246: *Drug Interactions and Adverse Effects*

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Clinical Instructor
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Thomas Jefferson University
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188: *Red Eye/Pink Eye*

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University of Ibadan and University College Hospital
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232: *Colorectal Disorders*

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39: *Physical Activity*

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256: *Gastrointestinal Allergy*

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71: *Children of Divorce*

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220: *Attention-deficit/Hyperactivity Disorder*

John M. Leventhal, MD, FAAP
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Yale University School of Medicine
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329: *Sexual Abuse of Children*

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42: *Safety and Injury Prevention*

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18: *Pediatric Imaging*

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271: *Hypocalcemia, Hypercalcemia, and Hypercalciuria*

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232: *Colorectal Disorders*

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128: *Anemia and Pallor*
181: *Petechiae and Purpura*

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145: *Edema*

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198: *Substance Use: Initial Approach in Primary Care*
336: *Substance Use Disorders*

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182: *Polyuria*

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315: *Pneumonia*

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255: *Gastroesophageal Reflux Disease*

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61: *Psychosocial Therapies*

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Carman and Ann Adams Endowed Chair in Pediatric Research
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Pediatrician-in-Chief, Children's Hospital of Michigan
Specialist-in-Chief, Department of Pediatrics, Detroit Medical Center
Scientific Member, Karmanos Cancer Institute, an NCI-designated Comprehensive Cancer Center
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163: *High Blood Pressure*
286: *Lipid Abnormalities*
361: *Heart Failure*

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80: *Perinatal Preventive Care: Fetal Assessment*
105: *Transient Metabolic Disturbances in the Newborn*
117: *Support for Families Whose Infant Is Sick or Dying*

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341: *Tuberculosis*

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269: *Hydrocephalus*

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341: *Tuberculosis*

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125: *Abdominal Pain*

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100: *Respiratory Distress and Breathing Disorders in the Newborn*
113: *Discharge Planning for the High-Risk Newborn Requiring Intensive Care*

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185: *Puberty: Normal and Abnormal*

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243: *Disorders of Sex Development*

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213: *Altitude Sickness*

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357: *Drug Overdose*

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69: *Caring for Families New to the United States*

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Carman and Ann Adam's Department of Pediatrics
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58: *Fluids, Electrolytes, and Acid-Base Composition*
353: *Dehydration*
360: *Head Injuries*

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271: *Hypocalcemia, Hypercalcemia, and Hypercalciuria*

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222: *Bacterial Skin Infections*

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135: *Cough*

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Pediatric Residency Director
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West Islip, New York
189: *School Absenteeism and School Refusal*

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96: *Common Congenital Anomalies*
148: *Facial Dysmorphism*
343: *Umbilical Anomalies*

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239: *Cystic Fibrosis*

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171: *Joint Pain*

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301: *Oliguria and Anuria*

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97: *Postnatal Assessment of Common Prenatal Sonographic Findings*

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302: *Oppositional Defiant Disorder*

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194: *Sleep Disturbances (Nonspecific)*

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143: *Dyspnea*

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Indiana Children's Health Service Research
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6: *Medical Home Collaborative Care*
7: *Planned Coordinated Care to Support the Medical Home*

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327: *Seizure Disorders*
374: *Status Epilepticus*

Edith A. McCarthy, MD
81: *Assisted Reproductive Technologies, Multiple Births, and Pregnancy Outcomes*

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234: *Congenital and Acquired Heart Disease*

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128: *Anemia and Pallor*

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174: *Loss of Appetite*
206: *Vomiting*

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2: *Practice Organization*

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78: *Homeless Children*

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287: *Lyme Disease*

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267: *Human Herpesvirus-6 and Human Herpesvirus-7 Infections*

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163: *High Blood Pressure*
286: *Lipid Abnormalities*

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182: *Polyuria*

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286: *Lipid Abnormalities*

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257: *Gastrointestinal Obstruction*
309: *Pectus Excavatum and Pectus Carinatum*

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257: *Gastrointestinal Obstruction*
309: *Pectus Excavatum and Pectus Carinatum*

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337: *Sudden Unexpected Infant Death*

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Minnesota Life Bridge
Cambridge, Minnesota
191: *Self-harm*

Robert E. Morris, MD, FAAP
Professor Emeritus
Department of Pediatrics
Mattel Children's Hospital
University of California, Los Angeles
Los Angeles, California
73: *Children in the Juvenile Justice System*

William Moss, MD, MPH
Professor
Department of Epidemiology, International Health and Molecular Microbiology and Immunology
Johns Hopkins Bloomberg School of Public Health
Baltimore, Maryland
268: *Human Immunodeficiency Virus Infection and Acquired Immunodeficiency Syndrome*

Richard T. Moxley III, MD
Professor of Neurology
Department of Neurology
University of Rochester Medical Center
Rochester, New York
293: *Muscular Dystrophy*

Daniel W. Mruzek, PhD
Associate Professor of Pediatrics
University of Rochester Medical Center
Rochester, New York
49: *Discussing Serious Symptoms, Results, and Diagnoses With the Patient and Family*

James A. Mulick, PhD, BCBA-D
Professor Emeritus of Pediatrics
The Ohio State University School of Medicine
Columbus, Ohio
221: *Autism Spectrum Disorder*

Upender K. Munshi, MBBS, MD, FAAP
Associate Professor of Pediatrics, Neonatology Division
Children's Hospital at Albany Medical Center
Albany, New York
110: *Identifying the Newborn Who Requires Specialized Care*

Nancy Murphy, MD, FAAP, FAAPMR
Professor of Pediatrics
Division Chief, Pediatric Physical Medicine and Rehabilitation
University of Utah Department of Pediatrics
Salt Lake City, Utah
226: *Cerebral Palsy*

Dennis L. Murray, MD, FAAP, PIDSA
Professor Emeritus of Pediatrics
Chief, Pediatric Infectious Diseases (Retired)
Georgia Regents University
Augusta, Georgia
236: *Contagious Exanthematous Diseases*

Suhas M. Nafday, MD, MRCP(Ire), DCH, FAAP
Associate Professor of Clinical Pediatrics
Albert Einstein College of Medicine
Director, Newborn Services and Therapeutic Hypothermia Program
Chair, Neonatal Performance Improvement and Co-Chair, Patient Safety
The Children's Hospital at Montefiore
Bronx, New York
98: *Abnormalities of Fetal Growth*
100: *Respiratory Distress and Breathing Disorders in the Newborn*

Gaurav Nanda, MD
Division of Pediatric Nephrology
Children's Hospital of Pittsburgh
Pittsburgh, Pennsylvania
344: *Urinary Tract Infections*

Joshua P. Needleman, MD
Maimonides Medical Center
Brooklyn, New York
Associate Professor of Clinical Pediatrics
Albert Einstein College of Medicine
Bronx, New York
208: *Wheezing*

Robert Needlman, MD, FAAP
Professor of Pediatrics
Case Western Reserve University School of Medicine
MetroHealth Medical Center
Cleveland, Ohio
74: *Children in Self-care*

Leonard B. Nelson, MD
Director of the Strabismus Center
Wills Eye Hospital
Co-Director Pediatric Ophthalmology and Ocular Genetics Department
Wills Eye Hospital
Philadelphia, Pennsylvania
214: *Amblyopia and Strabismus*

Sheri L. Nemerofsky, MD, FAAP
Assistant Professor of Pediatrics
Department of Pediatrics
Division of Neonatology
The Children's Hospital at Montefiore
Albert Einstein College of Medicine
Bronx, New York
90: *Care of the Late Preterm Infant*
97: *Postnatal Assessment of Common Prenatal Sonographic Findings*

Daniel R. Neuspiel, MD, MPH, FAAP
Clinical Professor of Pediatrics
University of North Carolina School of Medicine
Levine Children's Hospital
Charlotte, North Carolina
288: *Medical Errors, Adverse Events, and Patient Safety*

Hiep T. Nguyen, MD
Banner Children's Specialists–Urology
Cardon Children's Medical Center
Mesa, Arizona
299: *Obstructive Uropathy and Vesicoureteral Reflux*

Linda S. Nield, MD, FAAP
Professor of Pediatrics and Medical Education
Assistant Dean for Admissions
West Virginia University School of Medicine
Morgantown, West Virginia
219: *Atopic Dermatitis*
235: *Contact Dermatitis*
282: *Labial Adhesions*
335: *Stomatitis*

Michelle L. Niescierenko, MD
Instructor, Pediatrics and Emergency Medicine
Harvard Medical School
Boston, Massachusetts
248: *Enterovirus and Evolving Infections*

A. Barbara Oettgen, MD, MPH, FAAP
Assistant Professor of Pediatrics
Wayne State University School of Medicine
Children's Hospital of Michigan
Detroit, Michigan
312: *Phimosis*

Mary O'Hara, MD, FAAO, FACS, FAAP
Professor of Ophthalmology and Pediatrics
University of California, Davis
Sacramento, California
214: *Amblyopia and Strabismus*

Alexander L. Okun, MD, FAAP
Medical Director, New Alternatives for Children
New York, New York
67: *Palliative, End-of-Life, and Bereavement Care*

Karen Olness, MD, FAAP
Professor Emerita of Pediatrics, Global Health and Diseases
Case Western Reserve University School of Medicine
Cleveland, Ohio
48: *Providing Culturally Effective Care*
56: *Self-regulation Therapies: Hypnosis and Biofeedback*

Katherine Atienza Orellana, DO
Pediatric Gastroenterology
Valley Medical Group
Ramsey, New Jersey
125: *Abdominal Pain*

Craig C. Orlowski, MD
Associate Professor of Clinical Pediatrics
Division of Pediatric Endocrinology
University of Rochester School of Medicine and Dentistry
Rochester, New York
273: *Hypothyroidism*

Enrique M. Ostrea, Jr, MD
Professor of Pediatrics
Department of Pediatrics
Hutzel Women's Hospital
Children's Hospital of Michigan
Wayne State University School of Medicine
Detroit, Michigan
104: *Prenatal Drug Use: Neonatal Effects and the Drug Withdrawal Syndrome*

Philip Overby, MD, DABPN
Department of Pediatrics and Neurology
New York Medical College
Valhalla, New York
130: *Ataxia*

Philip O. Ozuah, MD, PhD
Professor of Pediatrics
Professor of Epidemiology and Population Health
Albert Einstein College of Medicine
President
Montefiore Health System
Bronx, New York
151: *Fatigue and Weakness*
162: *Hepatomegaly*
196: *Splenomegaly*
203: *Torticollis*

Donna M. Pacicca, MD, FAAP
Associate Professor of Orthopaedic Surgery
Adjunct Professor of Oral and Craniofacial Sciences
Children's Mercy Hospital
University of Missouri-Kansas City School of Medicine
Kansas City, Missouri
303: *Osteochondroses*

Lane S. Palmer, MD, FACS
Division of Pediatric Urology
Cohen Children's Medical Center of New York
Hofstra Northwell School of Medicine at Hofstra University
Long Island, New York
190: *Scrotal Swelling and Pain*

Debra H. Pan, MD
Assistant Professor of Pediatrics
Albert Einstein College of Medicine
Attending Physician
Division of Pediatric Gastroenterology and Nutrition
The Children's Hospital at Montefiore
Bronx, New York
170: *Jaundice*

Sanjay R. Parikh, MD, FACS
Division of Pediatric Otolaryngology
Seattle Children's Hospital
Associate Professor
Department of Otolaryngology–Head and Neck Surgery
University of Washington
Seattle, Washington
165: *Hoarseness*
251: *Foreign Bodies of the Ear, Nose, Airway, and Esophagus*

Sonia Partap, MD, MS, FAAP
Associate Professor
Department of Neurology
Stanford University
Palo Alto, California
269: *Hydrocephalus*

Alberto Pena, MD, FAAP
Clinical Professor of Surgery
Founder and Director, Colorectal Center for Children
Cincinnati Children's Hospital Medical Center
University of Cincinnati College of Medicine
Cincinnati, Ohio
232: *Colorectal Disorders*

James M. Perrin, MD, FAAP
John C. Robinson Chair in Pediatrics
MassGeneral Hospital for Children
Professor of Pediatrics
Harvard Medical School
Boston, Massachusetts
32: *Family Support*

Deborah Persaud, MD
Professor of Pediatrics
Division of Pediatric Infectious Diseases
Johns Hopkins University School of Medicine
Baltimore, Maryland
268: *Human Immunodeficiency Virus Infection and Acquired Immunodeficiency Syndrome*

Randall A. Phelps, MD, PhD, FAAP
Assistant Professor of Pediatrics
Child Development and Rehabilitation Center
Institute on Development and Disability
Oregon Health and Science University
Eugene, Oregon
278: *Intellectual Disability*

Joaquim M. B. Pinheiro, MD, MPH, FAAP
Professor of Pediatrics
Director, Neonatal-Perinatal Medicine Fellowship Program
Division of Neonatology
Albany Medical Center
Albany, New York
109: *Assessment and Stabilization at Delivery*

Steven W. Pipe, MD
Professor of Pediatrics and Pathology
Director, Pediatric Hematology and Oncology
University of Michigan
Ann Arbor, Michigan
355: *Disseminated Intravascular Coagulation*

Amy Pirretti, MS
32: *Family Support*

Leslie Plotnick, MD
Professor, Pediatric Endocrinology
Department of Pediatrics
Johns Hopkins Children's Center
Baltimore, Maryland
182: *Polyuria*
185: *Puberty: Normal and Abnormal*

Gregory A. Plotnikoff, MD, MTS
Penny George Institute for Health and Healing
Allina Health
Minneapolis, Minnesota
57: *Complementary and Integrative Medical Therapies*

Veronika Polishchuk, MD
Division of Pediatric Hematology/Oncology
The Children's Hospital at Montefiore
Bronx, New York
285: *Leukemias*

Gregory E. Prazar, MD, FAAP
Elliot Pediatric Specialists
New Hampshire Hospital for Children
Manchester, New Hampshire
201: *Temper Tantrums and Breath-holding Spells*
237: *Conversion Reactions and Hysteria*

Nathan Price, MD, FAAP
Clinical Assistant Professor
Stead Family Department of Pediatrics
Division of Pediatric Infectious Diseases
University of Iowa
Iowa City, Iowa
227: *Chickenpox*

David Pruitt, MD
Professor of Psychiatry and Pediatrics
Director, Division Child and Adolescent Psychiatry
University of Maryland School of Medicine
Baltimore, Maryland
62: *Psychotropic Medications in Primary Care Pediatrics*

E. Rebecca Pschirrer, MD, MPH
Associate Professor of OB/GYN and Radiology
Geisel School of Medicine at Dartmouth College
Hanover, New Hampshire
Clerkship Director of OB/GYN
Director of Obstetric Ultrasound and Prenatal Diagnosis
Division of Maternal Fetal Medicine
Dartmouth-Hitchcock Medical Center
Lebanon, New Hampshire
80: *Perinatal Preventive Care: Fetal Assessment*

Oscar H. Purugganan, MD, MPH, FAAP
Assistant Professor of Pediatrics
Department of Pediatrics
New York Presbyterian/Columbia University Medical Center
New York, New York
176: *Macrocephaly*
178: *Microcephaly*

Nadia K. Qureshi, MD
Assistant Professor of Pediatrics
Division of Pediatrics
Loyola University Medical Center
Chicago, Illinois
254: *Fungal Infections (Systemic)*

Andrew D. Racine, MD, PhD, FAAP
Senior Vice President and Chief Medical Officer
Montefiore Medical Center
Executive Director, Montefiore Medical Group
Bronx, New York
149: *Failure to Thrive: Pediatric Undernutrition*

Yaseen Rafee, MD
Assistant Professor of Pediatrics
Hurley Children's Hospital
Michigan State University, College of Human Medicine
East Lansing, Michigan
308: *Parasitic Infections*

Keyvan Rafei, MD
Medical Director, KinderMender Pediatric Centers
Columbia, Maryland
217: *Apparent Life-Threatening Events*

Jason R. Rafferty, MD, MPH, EdM
Triple Board Resident
Department of Psychiatry and Human Behavior
Brown University
Providence, Rhode Island
78: *Homeless Children*

Madhvi Rajpurkar, MD
Associate Professor
Carman and Ann Adams Department of Pediatrics
Wayne State University School of Medicine
Children's Hospital of Michigan
Detroit, Michigan
59: *Blood Products and Their Uses*
230: *Coagulation Disorders*

Prema Ramaswamy, MD
Director, Division of Pediatric Cardiology
Maimonides Infants and Children's Hospital of Brooklyn
Brooklyn, New York
200: *Syncope*

Cynthia Rand, MD, MPH, FAAP
Associate Professor, Pediatrics
Division of General Pediatrics
University of Rochester School of Medicine and Dentistry
Rochester, New York
20: *Immunizations*

Rajesh C. Rao, MD, FAAP
Professor of Ophthalmology
Section Head, Pediatric Ophthalmology
Oakland University William Beaumont School of Medicine
Royal Oak, Michigan
300: *Ocular Trauma*

Jawhar Rawwas, MD
Pediatric Hematology and Oncology
Children's Hospitals and Clinics of Minnesota
Minneapolis, Minnesota
274: *Immune (Idiopathic) Thrombocytopenia Purpura*

Sushma Reddy, MD
Assistant Professor of Pediatrics
Division of Pediatric Cardiology
Stanford University
Stanford, California
321: *Pyloric Stenosis*

Jennifer L. Reeve, MD, PhD, FAAP
Assistant Professor of Dermatology and Pediatrics
University of Michigan
Ann Arbor, Michigan
320: *Psoriasis*

Gloria Reeves, MD
Associate Professor
Division of Child and Adolescent Psychiatry
University of Maryland School of Medicine
Baltimore, Maryland
62: *Psychotropic Medications in Primary Care Pediatrics*

Kimberly J. Reidy, MD
Assistant Professor of Pediatrics
Division of Pediatric Nephrology
The Children's Hospital at Montefiore
Bronx, New York
160: *Hematuria*

Marina Reznik, MD, MS
Associate Professor of Pediatrics
Department of Pediatrics
The Children's Hospital at Montefiore
Albert Einstein College of Medicine
Bronx, New York
151: *Fatigue and Weakness*
162: *Hepatomegaly*
196: *Splenomegaly*

Robert L. Ricca, MD
Assistant Professor of Surgery
Division of Pediatric Surgery
Naval Medical Center Portsmouth
Portsmouth, Virginia
359: *Esophageal Caustic Injury*

Mark A. Riddle, MD
Professor of Psychiatry and Pediatrics
Johns Hopkins University School of Medicine
Baltimore, Maryland
62: *Psychotropic Medications in Primary Care Pediatrics*

Angel Rios, MD, FAAP
Professor of Pediatrics
Director of Neonatology
Department of Pediatrics
Division of Neonatology
The Children's Hospital at the Albany Medical Center
Albany, New York
106: *Specific Congenital Metabolic Diseases*

Yolanda Rivas, MD
Assistant Professor of Pediatrics
Albert Einstein College of Medicine
Attending Physician
Division of Pediatric Gastroenterology and Nutrition
The Children's Hospital at Montefiore
Bronx, New York
170: *Jaundice*

Ruby F. Rivera, MD, FAAP
Assistant Professor of Pediatrics
Albert Einstein College of Medicine
Attending Physician
Division of Pediatric Emergency Medicine
The Children's Hospital at Montefiore
Bronx, New York
140: *Dizziness and Vertigo*

John D. Roarty, MD, MPH, FAAP
Chief, Department of Ophthalmology
Children's Hospital of Michigan
Associate Professor of Ophthalmology
Wayne State University School of Medicine
Detroit, Michigan
300: *Ocular Trauma*

Brett W. Robbins, MD, FAAP
Director, Med-Peds Residency Program
Chief, Adolescent Medicine
University of Rochester Medical Center
Rochester, New York
4: *Evidence-based Medicine*

Sarah M. Roddy, MD, FAAP
Associate Professor of Pediatrics and Neurology
Associate Dean for Admissions
Loma Linda University School of Medicine
Loma Linda, California
179: *Nonconvulsive Periodic Disorders*
327: *Seizure Disorders*
374: *Status Epilepticus*

Victoria W. Rogers, MD, FAAP
Director, Let's Go! Program
Assistant Clinical Professor, Pediatrics, Tufts University School of Medicine
The Barbara Bush Children's Hospital at Maine Medical Center
Portland, Maine
5: *Quality Improvement in Practice*

Chokechai Rongkavilit, MD
Professor
Division of Pediatric Infectious Diseases
Wayne State University School of Medicine
Detroit, Michigan
248: *Enterovirus and Evolving Infections*
340: *Toxic Shock Syndrome*

Orna Rosen, MD, FAAP
Program Advisor
The Children's Hospital at Montefiore
Weiler Hospital
Division of Neonatology
Bronx, New York
96: *Common Congenital Anomalies*

Maris Rosenberg, MD
Children's Evaluation and Rehabilitation Center
Department of Pediatrics
Albert Einstein College of Medicine
The Children's Hospital at Montefiore
Bronx, New York
65: *Pediatric Rehabilitation*
195: *Speech and Language Concerns*

Lainie Friedman Ross, MD, PhD, FAAP
Carolyn and Matthew Bucksbaum Professor of Clinical Ethics
Professor
Departments of Pediatrics, Medicine, Surgery and the College
Associate Director, MacLean Center for Clinical Medical Ethics
University of Chicago
Chicago, Illinois
11: *Ethical and Legal Issues for the Primary Care Physician*

Michael Roth, MD
Assistant Professor of Pediatrics
Division of Pediatric Hematology, Oncology, Marrow and Blood Cell Transplantation
The Children's Hospital at Montefiore
Albert Einstein College of Medicine
Bronx, New York
285: *Leukemias*

Ann Rothpletz, PhD, CCC-A
Assistant Professor
Department of Otolaryngology–Head and Neck Surgery and Communicative Disorders
University of Louisville
Louisville, Kentucky
158: *Hearing Loss*

Arlene A. Rozzelle, MD, FACS, FAAP
Chief, Plastic and Reconstructive Surgery
Director, Cleft/Craniofacial Team
Director, Vascular Anomalies Team
Children's Hospital of Michigan
Associate Professor
Wayne State University School of Medicine
Detroit, Michigan
229: *Cleft Lip and Cleft Palate*

Paolo G. Rusconi, MD
Associate Professor of Pediatrics
Berenson Chair in Pediatric Cardiology
Medical Director
Pediatric Heart Failure and Transplant
University of Miami Miller School of Medicine
Miami, Florida
361: *Heart Failure*

Sarah Rush, MD
Director, Pediatric Neuro-Oncology
Akron Children's Hospital
Akron, Ohio
223: *Brain Tumors*

Francis E. Rushton, MD, FAAP
Clinical Professor of Pediatrics
University of South Carolina
Columbia, South Carolina
21: *The Essential Role of the Primary Care Pediatrician*

Camilla Sabella, MD, FAAP
Associate Professor of Pediatrics
Director, Center for Pediatric Infectious Diseases
Vice Chair, Education, Pediatric Institute
Cleveland Clinic Children's
Cleveland, Ohio
310: *Pertussis (Whooping Cough)*

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Professor of Pediatrics
Division of Gastroenterology, Hepatology and Nutrition
University of Cincinnati School of Medicine
Clinical Director, Schubert-Martin IBD Center
Cincinnati Children's Hospital Medical Center
Cincinnati, Ohio
276: *Inflammatory Bowel Disease*

Anca M. Safta, MD
Director, Pediatric Gastroenterology Program
Wake Forest Baptist Medical Center
Winston-Salem, North Carolina
259: *Gluten-Sensitive Enteropathy (Celiac Sprue)*

Paul J. Sagerman, MD, MS
Associate Professor, Pediatrics
Section of General Pediatric and Adolescent Medicine
Wake Forest School of Medicine
Winston-Salem, North Carolina
66: *Transitions to Adulthood*

Shashi Sahai, MD, FAAP
Pediatric Hospitalist
Sparrow Hospital
Lansing, Michigan
324: *Rheumatologic Diseases*

Joy Samanich, MD
Department of Pediatrics
Division of Genetics
The Children's Hospital at Montefiore
Bronx, New York
96: *Common Congenital Anomalies*
148: *Facial Dysmorphism*
343: *Umbilical Anomalies*

Oranee Sanmaneechai, MD
Pediatric Neurology Fellow
The Children's Hospital at Montefiore
Albert Einstein College of Medicine
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Assistant Professor of Pediatrics
Department of Pediatrics, Division of Neurology
Siriraj Hospital, Mahidol University
Bangkok, Thailand
107: *The Newborn With Neurologic Findings*

Indumathi Santhanam, MD, DCH
Professor and Head of Department
Pediatric Emergency Care
Institute of Child Health
Madras Medical College
Chennai-600008, India
363: *Hypoglycemia*

Richard M. Sarles, MD
Professor of Child and Adolescent Psychiatry and Pediatrics (Retired)
University of Maryland School of Medicine
Baltimore, Maryland
192: *Self-stimulating Behaviors*

Sharada A. Sarnaik, MD
Director, Comprehensive Sickle Cell Center
Children's Hospital of Michigan
Professor of Pediatrics
Wayne State University School of Medicine
Detroit, Michigan
262: *Hemoglobinopathies and Sickle Cell Disease*

Anirudh Saronwala, MD, MS, FAAP
Pediatric Resident
Kansas University School of Medicine
Wichita, Kansas
29: *Screening for Genetic-Metabolic Diseases*

Robert A. Saul, MD, FAAP, FACMG
Medical Director, General Pediatrics
Children's Hospital, Greenville Health System
Greenville, South Carolina
253: *Fragile X Syndrome*

Lawrence A. Schachner, MD
Senior Associate Dean and Executive Director for Development
Professor and Chair Emeritus and Stiefel Laboratories Chair
Director of the Division of Pediatric Dermatology
Department of Dermatology and Cutaneous Surgery
Professor, Department of Pediatrics
University of Miami Miller School of Medicine
Miami, Florida
326: *Seborrheic Dermatitis*

Eric Schaff, MD, FAAP
Medical Director, Child and Adolescent Medicine
Cherry Tree Pediatrics
Uniontown, Pennsylvania
123: *Contraception and Abortion*

Richard J. Schanler, MD, FAAP
Director, Neonatal Services
Cohen Children's Medical Center of New York and Northwell Health
Professor
Hofstra Northwell School of Medicine at Hofstra University
New Hyde Park, New York
88: *Breastfeeding the Newborn*

Miriam Schechter, MD, FAAP
Assistant Professor of Pediatrics
Albert Einstein College of Medicine
Department of Pediatrics
The Children's Hospital at Montefiore
Bronx, New York
146: *Epistaxis*

Steven C. Schlozman, MD
Assistant Professor of Psychiatry
Harvard Medical School
Associate Director
The Clay Center for Young Healthy Minds
Massachusetts General Hospital
Boston, Massachusetts
15: *Pediatric History: Assessing Functioning and Mental Health*

John P. Schmidt, MD, FAAP
Clinical Assistant Professor
Director, Division of Pediatric Hospital Medicine
Department of Pediatrics and Communicable Diseases
University of Michigan Health System
Ann Arbor, Michigan
Appendix B: *Outpatient Procedures*

Barton D. Schmitt, MD, FAAP
Director, Pediatric Call Center
Professor of Pediatrics
University of Colorado School of Medicine
Aurora, Colorado
247: *Encopresis*

Marcie Schneider, MD, FAAP, FSAHM
Greenwich Adolescent Medicine
Greenwich, Connecticut
216: *Anorexia Nervosa, Bulimia Nervosa, and Other Eating Disorders*

Cindy Schorzman, MD, FAAFP
Physician, Student Health and Counseling Services
University of California, Davis
Davis, California
75: *Gay- and Lesbian-parented Families*

Alan R. Schroeder, MD, FAAP
Director, PDCY
Santa Clara Valley Medical Center
San Jose, California
Clinical Associate Professor of Pediatrics (Affiliate)
Stanford University School of Medicine
Stanford, California
372: *Severe Acute Asthma (Status Asthmaticus)*

Scott A. Schroeder, MD, FCCP, FAAP
Department of Pediatrics
The Floating Hospital for Children at Tufts Medical Center
Boston, Massachusetts
133: *Chest Pain*
161: *Hemoptysis*

Cindy L. Schwartz, MD, MPH
Division Head and Chair of Pediatrics, ad interim
The Curtis Distinguished Professor of Pediatric Cancer
Professor, Departments of Pediatrics and Investigational Cancer Therapeutics
The University of Texas M.D. Anderson Cancer Center
Children's Cancer Hospital
Houston, Texas
225: *Cancers in Childhood*

Robert P. Schwartz, MD, FAAP
Professor Emeritus of Pediatrics
Wake Forest School of Medicine
Winston-Salem, North Carolina
31: *Applying Behavior Change Science*

Kathleen B. Schwarz, MD
Professor of Pediatrics
Director, Pediatric Liver Center
Professor of Pediatrics
Johns Hopkins University School of Medicine
Baltimore, Maryland
265: *Hepatitis*

Richard M. Schwend, MD, FAAP
Professor of Orthopaedics and Pediatrics
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Director of Research
Children's Mercy Hospital
Kansas City, Missouri
97: *Postnatal Assessment of Common Prenatal Sonographic Findings*

W. Frederick Schwenk II, MD
Professor of Pediatrics
Division of Pediatric Endocrinology
Mayo Medical School
Rochester, Minnesota
241: *Diabetes Mellitus*
354: *Diabetic Ketoacidosis*

Elizabeth Secord, MD
Professor of Pediatrics
Division Chief and Training Program Director
Allergy and Immunology
Wayne State University School of Medicine
Children's Hospital of Michigan
Detroit, Michigan
350: *Anaphylaxis*

Robert T. Seese, MD, FAAP
Division of Ambulatory Pediatrics
Assistant Professor of Clinical Pediatrics
The Ohio State University School of Medicine
Columbus, Ohio
325: *Rocky Mountain Spotted Fever*

Robert Sege, MD, PhD, FAAP
Senior Fellow
The Center for the Study of Social Policy
Washington, DC
Vice President, The Medical Foundation Division
Health Resources in Action
Boston, Massachusetts
44: *Violence Prevention*

George B. Segel, MD
Professor of Medicine
Emeritus Professor of Pediatrics
University of Rochester School of Medicine
Rochester, New York
175: *Lymphadenopathy*

Elizabeth A. Sellars, MD, FAAP
Assistant Professor
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313: *Pierre Robin Sequence*

Catherine R. Sellinger, MD, FAAP
Assistant Professor of Clinical Pediatrics
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Associate Director, Division of Pediatric Emergency Medicine
Department of Pediatrics
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Bronx, New York
140: *Dizziness and Vertigo*

Aimee E. Seningen, MD
First Steps Pediatrics and Adolescent Medicine
Pittsburgh, Pennsylvania
119: *Interviewing Adolescents*

Usha Sethuraman, MD
Program Director, Pediatric Emergency Medicine Fellowship Program
Associate Professor
Division of Emergency Medicine
Carman and Ann Adams Department of Pediatrics
Children's Hospital of Michigan
Detroit, Michigan
362: *Hypertensive Emergencies*

M. Mohsin Shah, MD
Director of Neurotrauma
Natividad Medical Center
Salinas, California
Director of Neurotrauma and Neurocritical Care
Orange County Global Medical Center
Santa Ana, California
364: *Increased Intracranial Pressure*

Anjali A. Sharathkumar, MBBS, MD, MS
Associate Professor of Pediatrics, University of Iowa Carver College of Medicine
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Director, Iowa Hemophilia and Thrombosis Centre
Stead Family Department of Pediatrics, University of Iowa Children's Hospital
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355: *Disseminated Intravascular Coagulation*

Ruchika Sharma, MD
Joan Pediatric Hemostasis-Thrombosis Fellow
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27: *Screening for Anemia*

Judith S. Shaw, EdD, MPH, RN, FAAP
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Executive Director, Vermont Child Health Improvement Program
University of Vermont College of Medicine
Burlington, Vermont
45: *Conducting the Health Supervision Visit*

Katherine M. Shea, MD, MPH
Consultant in Children's Environmental Health
Chapel Hill, North Carolina
19: *Environmental Health: The Role of the Primary Care Physician*

Robert L. Sheridan, MD, FACS
Burn Service Medical Director, Boston Shriners Hospital for Children
Division of Burns, Massachusetts General Hospital
Department of Surgery
Harvard Medical School
Boston, Massachusetts
375: *Thermal Injuries*

Rashmi Shetgiri, MD, MSHS
Assistant Professor of Pediatrics
David Geffen School of Medicine at UCLA
Los Angeles Biomedical Research Institute at Harbor–UCLA Medical Center
Torrance, California
69: *Caring for Families New to the United States*

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Department of Research
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Rochester, New York
8: *Health Literacy*

Lisa H. Shulman, MD, FAAP
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Bronx, New York
65: *Pediatric Rehabilitation*

David M. Siegel, MD, MPH, FAAP
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Professor of Pediatrics
University of Rochester School of Medicine and Dentistry
Rochester, New York
171: *Joint Pain*
324: *Rheumatologic Diseases*

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William Beaumont Hospital
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Rochester, Michigan
President
Secretory IgA, Inc.
Ann Arbor, Michigan
350: *Anaphylaxis*

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Winston-Salem, North Carolina
292: *Münchausen Syndrome by Proxy: Medical Child Abuse*

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251: *Foreign Bodies of the Ear, Nose, Airway, and Esophagus*

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Chapter 1

HEALTH CARE DELIVERY SYSTEM

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Health care services accessibility, the content and quality provided, and outcomes occur within the context of the health care delivery system. Findings from child health services research provide pediatricians with an increasingly accurate and complete picture of how health care affects child health, development, and well-being. Understanding how pediatric services improve child health should begin with examining the structure of the delivery system and processes that occur once health professionals and patients interact.

This chapter uses a structure-process-outcome framework to describe the health care delivery system and to analyze its effects on children. *Structure* refers to the organizational and financial arrangements that are present before health professionals and patients interact. Structural elements include the pediatric workforce, delivery sites (including the medical home), information technology, and financing of services. The delivery, or *process*, of care occurs when patients come into contact with providers or suppliers. The number and content of visits (utilization), the costs of these services, patients' evaluations of and satisfaction with these services, and the volume and types of surgical procedures are all examples of processes of care. The end results of the health care delivery process are patient *outcomes*: changes in health, functional status, and well-being. The degree to which health care is consistent with the best available medical evidence and linked to positive and desired health outcomes determines the level of quality of care.

HEALTH CARE DELIVERY SYSTEM

Overview and Financing

Health care services in the United States are delivered within a complex system. In 2013, the United States spent $2.9 trillion on health care, amounting to 17.4% of total economic output for the nation, and equal to $9,255 per person. The ultimate source of all funding for health care is from a portion of workers' total compensation directed to health benefits or from taxes collected. Health care services are consumed by individuals but paid for through a combination of private and public insurance coverage, out-of-pocket spending, and public health programs. Over one-half (55%) of all health care is directly paid for by the private sector, but indirect financing via tax deductions means that the federal, state, and local governments actually contribute more than half of all spending (54% if the federal tax deduction for health insurance premiums is moved from the private side to the public side of the ledger). Growth in health care spending in the United States has been a significant concern during the past several decades. These concerns culminated most recently in the 2010 passage of the Patient Protection and Affordable Care Act of 2010 (ACA), which is viewed as the most comprehensive package of changes and reforms to the US health system in decades.

Although most children have health insurance coverage through their parents' employer-based health insurance or another private source (54%), many children (37%) have publicly sponsored coverage through Medicaid and the Children's Health Insurance Program (CHIP). On average, children younger than 18 years receive one-fifth of the public spending on health services. Despite their representing one-third of the population, just 15% of personal health care spending ($285 billion, 2010 data) was on children. This equates to $3,628 per child, which is 60% of the spending on 19- to 64-year-olds and one-fifth of the spending on those older than 65 years. As with adults, the largest category of spending for children's health care was on hospital services ($121 billion) followed by physician and clinical services ($76 billion). Increasing numbers of children are taking prescription medications, with rising expenditures in that area over time ($18 billion in 2010), which is also similar to adults. Also, like adults, a small percentage of children consume a disproportionate share of health spending. For example, in the Medicaid and CHIP programs, the top 10% of enrollees consumed 72% of total spending. Two-thirds of these children have chronic conditions.

Child Health Care Delivery Sites

Children receive health care services in a wide variety of inpatient and outpatient settings. Although home visits and home-based care were once commonplace in the United States, most pediatric professionals no longer make house calls. Select populations of higher-risk families (eg, teen mothers) or higher-risk infants (eg, those with poor weight gain, borderline elevated bilirubin in newborns) may receive home care visits, but most formal medical care is not provided at home. In other countries, however, nurse home visitation, particularly for families of newborn and infant children, is a routine part of pediatric primary care.

Inpatient Care Facilities

Hospitals have changed dramatically during the past 20 years in response to financial pressures to reduce lengths of stay and rates of admission. Many hospitals now offer a wide range of services across multiple sites integrated in a network, including inpatient care, outpatient diagnostic procedures, surgery, and outpatient physician visits. Up to 28% of hospitals are part of systems, defined by the American Hospital Association (AHA) as "a group of hospitals, physicians, other providers, insurers and/or community agencies that work together to coordinate and deliver a broad spectrum of services to their community." Whereas all inpatient care occurs in hospitals, hospital care can no longer be equated with inpatient care. Many hospitals have become integrated delivery systems that provide primary care, specialty care, ancillary services, and inpatient care.

There are 5,686 registered hospitals in the United States, including 4,986 nonfederal, short-term general and specialty hospitals. The remaining hospitals are psychiatric (406), federal (213), long-term care (81), and parts of institutions, such as prisons or college infirmaries. Among the nonfederal short-term hospitals, 2,904 are private not-for-profit hospitals (58%), 1,010 (20%) are state- or local-government-owned hospitals, and 1,060 (20%) are for-profit (investor-owned) hospitals. Not-for-profit status exempts institutions from paying taxes and allows them to borrow money in the tax-exempt bond market. In return, nonprofit hospitals are expected to provide community benefit, such as unreimbursed care to patients without insurance or community health programs. Twenty percent of hospitals are teaching hospitals affiliated with one of the nation's 134 allopathic medical schools. Most teaching hospitals are urban, whereas most of the nation's rural hospitals are small institutions with fewer than 100 beds.

Approximately 250 (5%) of US hospitals are considered children's hospitals. There are approximately 50 freestanding acute care children's hospitals, nearly all of which are teaching hospitals. There are approximately 100 joint children's hospitals, which are large pediatric programs in larger medical centers. Approximately 40 freestanding children's rehabilitation, specialty, and convalescent hospitals provide care to children in 16 short-term facilities and 24 long-term facilities. Finally, approximately 50 freestanding children's psychiatric hospitals provide mental health services to children and adolescents at 10 short-term and 40 long-term care facilities. The remaining majority of inpatient pediatric admissions occur at general hospitals.

In 2010, there were 35.1 million hospital discharges in the United States, including 3.8 million newborns. Excluding newborn admissions, there are approximately 2.0 million hospitalizations per year for infants and children younger than 16 years old. Children's hospitals account for 40% of pediatric inpatient days and 50% of the costs of childhood hospitalization in the United States ($10 billion each year). The remaining majority of children, therefore, are hospitalized in general hospitals with and without pediatric units. Many smaller, rural hospitals are no longer operating pediatric units because of insufficient demand.

According to data from the Children's Hospital Association (formerly National Association of Children's Hospitals and Related Institutions), children's hospitals care for the sickest pediatric patients. Children's hospitals have diverse patient populations, with acute illness or acute exacerbation of illness accounting for many short admissions and complex illness or complex chronic conditions accounting for longer stays among fewer admissions. The median length of stay at children's hospital is in the 2- to 3-day range, but the mean is in the 5- to 7-day range. Children residing in low-income communities are more likely to be admitted to the hospital via the emergency department compared with those from higher-income residences.

Coordination of care for hospitalized children is a complex task that involves many health professionals. Because most pediatric inpatient care is infrequent and brief, it is important that it be managed and linked to the child's primary medical home. This requires communication between the hospital physicians and the primary care pediatrician, as well as involvement of the family, meticulous and seamless hand-offs, and clear delineation of responsibilities at each stage in the care process.

Methods of payment for hospital services continue to evolve in the United States. Changes occurred in the early 1980s when the prospective payment system was instituted in the Medicare program. Hospital payment shifted from a cost basis (payment for each service billed) to a fixed fee based on the principal problem managed during the hospitalization (known as the diagnosis-related group [DRG]). This DRG-based payment system paid hospitals the same amount of money for all patients with the same diagnosis and severity, regardless of how long they stayed or what services were provided. DRGs provided financial incentives to shorten lengths of stay. The introduction of the DRG-based hospital payment system stimulated the proliferation of large outpatient specialty and surgical centers. Today the United States has one of the lowest hospital admission rates and among the lowest average hospital occupancy rates throughout all developed nations. Another hospital payment model is per diem, whereby hospitals are paid a set amount for each day a patient is hospitalized, again regardless of what services are provided. Contracts may have higher payments for days in intensive care units but may also have blended rates that pay the same amount for any location or level of service. Per diem contracting is typically linked to utilization review, in which case insurers review the level of care provided and need for hospital services. Children's hospitals face an array of payment methods, unlike adult hospitals, which primarily encounter Medicare DRG payments, or private insurance contracts that echo the DRG structure from Medicare. DRG or case-based payment is a growing trend in pediatric hospitals and is expected to increase the need for hospitals to operate efficiently.

Outpatient Care Facilities

Outpatient visits for children occur in a large variety of publicly and privately owned facilities. Approximately 88% of primary care visits among children occur at physician's offices, 8% in hospital primary care clinics, and 4% in community health centers. Children may also receive care in school-based health centers, emergency departments, urgent-care centers, and, most recently, retail-based clinics located in drug stores and stores such as CVS, Wal-Mart, and Target. Unfortunately, services that occur in these varied settings are challenging to coordinate with services for the same patient that occur in the medical home.

Practice Organizations and Locations

Pediatric physician organizations can be categorized into solo practice, group practice (single-specialty practices with general pediatricians only and multispecialty groups, which include general pediatrics and other types of specialties), health maintenance organizations, hospital-based practices, and freestanding emergency departments. The practice locations for office-based pediatricians in 2013 are shown in Table 1-1.

Table 1-1 Practice Settings for Office-Based Pediatricians, 2013

TYPE OF PRACTICE SETTING	PERECENTAGE OF PRACTICE TYPE
Solo/2-physician group	12
Pediatric group, 3-10 physicians	26
Pediatric group, >10 physicians	6
Multiple-speciality group	12
Health maintenance organization (staff/group model)	2
Hospital/clinic	14
Medical school	18
Community health center	3
Other (eg, freestanding emergency department)	5

From American Academy of Pediatrics Periodic Survey of Fellows. Pediatrician's Practice and Personal Characteristics: US only, 2013. Percent of Pediatricians by Primary Employment Setting (Table 3). Available at: www.aap.org/en-us/professional-resources/Research/pediatrician-surveys/Pages/Personal-and-Practice-Characteristics-of-Pediatricians-US-only.aspx. Accessed September 8, 2015.

Once common, solo practice is now in decline. During the interval between 1996 and 2005, the proportion of visits to physicians who were in solo = 2-physician practices decreased 8.2%, whereas visits to physicians who were part of a group practice with at least 6 physicians increased by 4.5%. Historically, a single physician could provide high continuity of care for patients. Although this autonomy and continuity appeal to some physicians, they also require an individual facility with the operational and financial aspects of health care delivery, which have grown increasingly complex. Solo physicians also have a more difficult time arranging for after-hours, weekend, and vacation coverage than their group practice peers. Pediatricians entering the medical marketplace are increasingly concerned not only with their incomes but also with such quality-of-life factors as time spent in the office, vacation, and coverage flexibility. Other benefits of group practice include administrative economies of scale, more stable cash flow, stronger negotiating position with health plans, greater financial reserves that may facilitate investments in practice improvements such as health information technology, and the possibility of physicians developing areas of special expertise, which is useful for both primary care and specialty practices.

Private pediatric providers may be paid through fee-for-service payments for each office visit or outpatient service provided. This is the predominant form of payment for non–managed care private insurance primary care and nearly all specialty care. Capitated payments consist of fixed dollar payments to physicians on a per-member per-month basis, regardless of actual use by patients. This form of contracting is most common for Medicaid managed care programs and commercial health maintenance organizations. To gain efficiencies of scale for administrative expenses and greater leverage for negotiations with payers, practices may organize into Independent Practice Associations (IPAs) or Group Practice Without Walls (GPWW). An IPA is a third-party physician-directed joint venture that allows contract negotiations and collaborative activities by practices that maintain separate tax identifications. It is the loosest form of multiple-practice organization, primarily formed to gain contracting leverage for physician services with managed care organizations. A GPWW is formed when private physicians form a new legal entity to develop and control a professional corporation but maintain separate office locations and direct operational control of their support staffs, equipment, records, and patient relationships. The GPWW has more centralized control, with a board and management structure, than does an IPA. In recent years, hospitals and health systems have also increased their purchase of physician practices, an activity seen in both adult and pediatric ambulatory practices.

Community health centers are one component of the federal government's consolidated Health Center Program that also includes homeless health centers, centers in public housing, and migrant health centers. For more than 35 years, the Bureau of Primary Healthcare within the US Department of Health and Human Services, the Health Resources and Services Administration, has provided federal support for health center programs. These resources are used to fund services for medically underserved populations, particularly uninsured children and their families, immigrant and seasonal farm workers and their families, homeless persons, public housing residents, and those needing school-based health care. Community health centers focus on providing comprehensive primary health care to persons in medically underserved areas. The proportions of visits made to community health clinics and hospital clinics are much higher for the uninsured and minority racial and ethnic groups because of poorer access to physician practices for these groups. There are 1,250 community health centers that care for 20 million Americans with limited financial resources. It is estimated that they save the nation up to $17.6 billion through preventive care and decreased use of emergency departments. Community health centers have received significant increases in funding during the past decade, and several provisions in the ACA provided funds and demonstration projects that include them.

Several other public sector *safety-net* provider systems offer health care services for uninsured and underinsured pediatric patients. These entities include local public health departments, community and migrant health centers, public hospital systems, and school-based clinic systems. In addition, many not-for-profit organizations assist in meeting the health care needs of uninsured and underinsured children.

Access to and Utilization of Outpatient Services

More than three-quarters of children have at least 1 visit to a physician's office each year, 6% visit physicians in a hospital clinic, and 18% have 1 or more emergency department visits. Many studies have documented that children make fewer than the number of health assessment visits recommended by the American

Academy of Pediatrics (AAP). Barriers to accessing outpatient services are a chief cause of this underuse. A most important barrier to accessing care is limited availability of pediatric providers in some geographic regions, which has at its root decreased financing of pediatric care. A shortage of pediatricians in rural areas is linked to the maldistribution of pediatricians nationally, in part because of challenges of financial viability in rural areas. The effects of payment levels are also seen in all parts of the country for other services, including pediatric specialty care, mental health services, and dentistry. For example, use of dentists in the United States remains low, with just 40% of children seeing a dentist annually, a consequence of lack of adequate financing for these services. For other types of services, children's insurance may not fully cover the office visit. (Lack of coverage among insured persons for needed services is a problem that has been labeled *underinsurance*.) Additional access barriers to seeking outpatient care include geographic access problems (lack of pediatricians in the community or difficulty traveling to the practice site) and organizational access problems (eg, for non-native English speakers, a lack of interpreters, limited after-hours care, or long appointment waits).

One-parent families and those with 2 working parents make up most of the families in the United States. To maintain access to services with these logistical barriers in mind, practices have extended their office hours to provide coverage during evenings and on weekends, in addition to on-call coverage at night. This trend is a departure from the office hours that pediatricians traditionally provided. After-hours coverage is provided in settings that are convenient, such as using the pediatrician's own office or an examination suite at the local community hospital. Many pediatricians join with their colleagues in sharing after-hours or weekend coverage. They take turns covering the telephone and meeting patients' needs, with prompt referral back to the patient's designated physician. This approach provides efficient off-hours medical care and affords each physician more time for other activities.

Distribution, Practice Locations, and Access to Pediatric Care

Pediatrics is widely viewed as the principal specialty responsible for setting child health care policy and ensuring the health of the nation's children. Between 1996 and 2006, the percentage of visits to general pediatricians by children and adolescents aged 17 and younger increased from 61% to 71%, whereas the percentage of visits to nonpediatric generalists (eg, family physicians) decreased from 28% to 22%. Notably, between 2000 and 2006, the proportion of visits for adolescents changed most, with 53% of visits to general pediatricians in 2006, up from 38% in 2000. The percentage of visits to pediatric specialists for these patients increased from 2% to 5%, whereas the percentage of visits to nonpediatric specialists declined from 22% to 12%. These data suggest that more children, especially adolescents, are receiving care from general and specialized pediatricians. These data, however, must be interpreted with caution as they represent proportions, rather than rates per child. Although certain conditions may be better suited to care of pediatric specialists, there are limited data on improved outcomes for children cared for by pediatric specialists versus adult specialists, especially among older children and youth. One exception, among several, is the field of cardiology, where adult cardiologists are generally not trained to care for patients with congenital heart disease. As pediatric care increases survival of patients such as these, new demand will emerge for specialists who can transition children into adolescence and adulthood, with knowledge of the physiology and pathology of diseases and their adult sequelae, for example, physicians trained in both internal medicine and pediatrics (med-peds physicians).

On average, 1 certified general pediatrician can be found for every 1,300 children throughout the United States. This ratio is generally deemed to be an adequate supply of pediatricians overall, particularly given the higher growth in the number of pediatricians compared with the rate of growth of children. However, the statistic does not reflect important regional variation in the supply of pediatricians, with many rural and inner-city areas experiencing child health professional shortages. Approximately 1 in 10 children live in an area without a pediatrician. As of 2006, 1 million children lived in areas with no local pediatrician. Eighteen states had ABP-certified physician-to-child ratios of less than 0.1 per 100,000 children (which is rounded to 0 by the American Board of Pediatrics [ABP]) in 1 of 13 fields: adolescent medicine (8), cardiology (1), child abuse pediatrics (7) critical care medicine (1), development-behavioral medicine (4), emergency medicine (4), endocrinology (1), gastroenterology (1), hematology-oncology (1), infectious diseases (3), nephrology (3), pulmonology (3), and rheumatology (12). Although not considered a pediatric subspecialty, there are also shortages for child neurology and child and adolescent psychiatry.

Only 8% of pediatricians in the United States practice in rural communities to care for the 19% of the childhood population that lives there. By contrast, the 30% of children who live in large metropolitan areas are cared for by almost 54% of practicing pediatricians. The remaining 37% of pediatricians practice in suburban settings, serving 34% of the nation's children. Several factors have led to this maldistribution of pediatricians, but financial viability of practice in rural areas is one challenge. Except for pediatricians practicing in sparsely populated areas, which have limited hospital and technical support services and few pediatric specialists, pediatricians generally practice similarly throughout the United States. These professionals, like those in other specialties, tend to settle in areas that have a higher per capita income.

Medical Home

The pediatric primary care patient-centered medical home (PCMH) is important for all children, not simply those who have long-term special health care needs. In addition to providing routine preventive services, anticipatory guidance, and acute care, the medical home adds several components to the conventional

examination room–based model of primary care: registries of patients with specific diseases to better facilitate ongoing chronic care management; care coordination processes that link children and families to appropriate medical, social, and community services; active and integrated comanagement between primary and specialty care; and patient education, particularly for patients with chronic and psychological disorders. The medical home should be easily accessible for patients, promote continuity of care, provide a wide range of services to meet most of the needs of children, and coordinate care received in all locations. These functions—access, continuity, comprehensiveness, and coordination—are the core attributes of primary care as defined by the Institute of Medicine. Research evidence demonstrates that when these functions are attained at a high level, children are less likely to be hospitalized for health problems that might be managed in outpatient settings, families report greater satisfaction with care, and health care costs are reduced. Widespread adoption of the PCMH model, however, calls for a more rational and enhanced payment for primary care services to replace the current episodic and volume-driven payment mode. (For a comprehensive discussion regarding the medical home, see Chapter 6, Medical Home Collaborative Care.)

Patient Call Centers or After-Hours Programs

Pediatric call centers or after-hours programs (AHPs) have been established in all areas of the United States. Patients greatly value ready access to medical advice outside of office hours, a trend that has grown with the rise of families with 2 parents in the workforce. AHPs are staffed by trained personnel on nights, weekends, and holidays. They give advice for symptomatic care and appropriate prescription refills, make referrals to an emergency facility or to an after-hours pediatric office, or advise seeing the patient's own pediatrician during office hours. AHPs operate under professional oversight, using standardized protocols provided by pediatricians who use their services. In many instances, health care systems subsidize AHPs on behalf of their network of pediatricians because of the efficiency and cost savings attributed to them. In a large, multicenter study, 65% of parents reported no preference about speaking with a physician or nonphysician for after-hours care, but 28% indicated a preference to speak with a physician. More than 80% of parents follow through with recommendations made by the call center professionals.

PEDIATRIC WORKFORCE

Pediatrics and children's health care are not synonymous. A pluralistic mix of pediatricians, internal medicine, family medicine, pediatric specialists, and nonphysician clinicians provide services to the nation's children. Key trends in the pediatric workforce include: sustained interest in the field among graduating medical students; more rapid growth in pediatricians than the population of children in the United States; the dominance of women in the field; the importance of international medical graduates to the pediatric workforce, especially the subspecialty workforce; and a geographic maldistribution of physicians, particularly subspecialists but also primary care physicians.

Physicians, Pediatricians, and Pediatric Specialists

In 2013 the total number of licensed physicians in the United States was approximately 829,962, with 56,282 (7%) self-designating as pediatricians. Approximately 70% of self-designated pediatricians obtain board certification from the ABP, and 53,697 were board certified in 2007 according to the American Medical Association. Among certified general pediatricians, 20,138 (38%) have an additional certificate in a pediatric subspecialty.

Across all medical specialties, women constitute 33% of all physicians, but they represent 60% of pediatricians. Currently, 73% of pediatric resident trainees are women compared with only 30% in 1975. Historically, more men entered pediatric subspecialties, but this is changing. The rise in the number of female pediatricians is one of the more impressive and important trends shaping the pediatric workforce. Women are more likely than men to work part-time, and they spend fewer hours in direct patient care over their work lives. To maintain the same number of full-time equivalent physicians, more pediatricians may need to be trained each year in the future if the proportion of women in pediatrics remains as high as it is now or even increases.

Between 1993 and 2009 the proportion of pediatricians working part-time increased from 11% to 24%. On average, however, the way in which pediatricians spent their time was constant between these years. In 2010 office-based pediatricians worked 48 hours per week, spending approximately 34 of these hours in direct patient care, 6 in administration, 3 in academic medicine, 2 in research, and 2 in fellowship training. The allocation of time, however, is heterogeneous. Those in predominantly clinical roles may spend all their time on patient care and related administration, whereas those in academic settings may spend 50% to 80% of their time on research and/or teaching. For example, only 59% of certified pediatric subspecialists' time is spent in direct patient care. The remainder is spent in research, teaching, and administration. This is because 60% practice in academic health centers, contrasting with fewer than 33% of internal medicine subspecialists who do so. The perceived or required need to practice subspecialties in pediatrics at academic medical centers has implications for geographic distribution of these physicians, the clinical work hours they offer, and incentives for choosing the field as a career. Increasing numbers of pediatricians practice part-time, with those physicians reporting an average of 25 hours per week of direct clinical care.

Physician Training for Pediatrics

The traditional path to medical practice in pediatrics includes completion of 4 years of undergraduate studies, 4 years of medical school (or more if in a dual-degree program), and 3 years of residency training in

pediatrics. The current structure and processes of medical education are rooted in early 20th-century "reforms" following the Flexner report. In the past 2 decades, questions have been raised about the relevance of the training model given the current and future nature of medical science and health care delivery. Medical students and physicians also do not receive training in the economics or business of health care delivery of medical practice.

Consumers and providers of health services differ in the priorities they place on the 3 main challenges of the health care delivery system: ensuring *access* to care, controlling *costs,* and improving the *quality* of care. Costs of and access to medical care are of prime importance to consumers, who tend to assume that quality of care will always be good. In contrast, neither access nor cost has been an important component of medical school training, which focuses almost exclusively on how to make a diagnosis; how to support this diagnosis with appropriate information from the history, physical examination, and laboratory findings; and how to institute treatment that is appropriate to the diagnosis. The nature of most educational settings (university based, research oriented, with generally a highly specialized faculty) is responsible for a medical educational process that focuses largely on the biological bases of disease. In contrast, relatively little attention is devoted to understanding the social, occupational, and environmental causes of ill health, although issues such as these are major determinants of disease and dysfunction or patients' subjective assessment of their own health.

Residency Training

After medical school (referred to as undergraduate medical education), approximately 14% of medical school seniors select a pediatric training program (graduate medical education, or GME). There are 123,310 on-duty residents in the United States, among whom 7% are training in pediatrics. In academic year 2014–2015, there were 199 programs accredited according to the Accreditation Council for Graduate Medical Education, or ACGME for general pediatric residency training in the United States and another 17 in Canada. There were 8,979 on-duty pediatric residents in academic year 2014–2015 according to the ACGME; according to the ABP, there were 9810 residents in training in 2014. These differences are the result of trainees in combined programs, such as child neurology, as well as special tracks, such as research. When compared with 1999 figures, this growth is a 23% increase in the absolute number of pediatric residents, a rate of rise that far exceeds the proportional increase in the number of children in the country. Interest in pediatrics as a career choice continues to be strong.

In 1967 the ABP and the American Board of Internal Medicine (ABIM) agreed that individuals who had 2 years of general internal medicine and 2 years of general pediatrics were eligible for board certification in both specialties. In 2014–2015, there were 79 accredited for combined med-peds residency in the United States; these programs have 1,477 on-duty residents. The percentage of women enrolled is less than in categorical pediatrics and has been stable over the last few years at about 58%. In rural communities or small towns, the med-peds physician may play a role as a consultant in the care of high-risk newborns and children who have a chronic illness or as a hospitalist for children and adults. These physicians may subspecialize in fields with larger numbers of children with chronic illnesses of childhood who are surviving into adulthood. In other markets, internal medicine and pediatric practices can use the med-peds physician to attract new patients, especially adolescents and families desiring health care for everyone in the same practice. Because med-peds physicians can alter their practice according to patient demand, the amount of pediatric care that these health professionals will provide will likely decrease with the aging of the population and the growing cohort of adult survivors of congenital and chronic childhood illness. Upon completion of residency, trainees are eligible to sit for the pediatric certifying exam ("board eligible"). They may enter practice in general pediatrics on an inpatient or outpatient basis or continue training in a fellowship program for further specialization.

Pediatric Specialization

In 2014, 59% of first-time general pediatrics test-takers selected a career as a general pediatrician, 30% a career in a pediatric subspecialty, and 5% a career in another nonpediatric specialty. In addition to general pediatrics, 20 areas of pediatric subspecialization are certifiable by the ABP (Table 1-2). The absolute number of subspecialty trainees has nearly doubled since 1999. 1996 and 2003. In 2014–2015, there were 1,541 first-year, 1,386 second-year, and 1,293 third-year fellows in pediatric subspecialty training. By comparison, in 1999–2000, there were 796 first-year fellows (in fewer specialty training programs). The top 5 career choices among pediatric subspecialty fields are neonatal-perinatal medicine, critical care medicine, hematology-oncology, cardiology, and emergency medicine. Women graduating from medical schools more recently are more likely than their older female counterparts to choose a subspecialty career, although male physicians still predominate within most subspecialties.

In general, primary care salaries are lower than those for specialists, although the differences are not as stark in pediatrics as in adult medicine. For the first 3 to 5 years after residency, primary care physicians can be expected to have expenses that exceed earnings.

International Medical Graduates

International medical graduates (IMGs) constitute an important share of the pediatric workforce. IMGs receive their undergraduate medical education abroad but complete their residency in the United States. In 2014, IMGs accounted for 25% of all general pediatricians (vs 24% of all US physicians). Nearly 1 in 3 board-certified pediatric subspecialists are IMGs. Pediatrics is the third-highest specialty among IMGs (8.5%), representing growth from 1980 when it was fifth highest (6.8%). The subspecialties with the greatest proportions of IMGs are geriatric medicine (50%), nephrology (45%), and international cardiology (43%).

Table 1-2 Number of Board-Certified Pediatric Subspecialists Through 2014

PEDIATRIC SUBSPECIALTY*	NUMBER CERTIFIED
Adolescent medicine (1994)[S]	650
Cardiology (1961)[S]	2,947
Child abuse and pediatrics (2009)[S]	324
Critical care medicine (1987)[S]	2,377
Developmental-behavioral pediatrics (2002)[S]	720
Emergency medicine (1992)[S]	2,046
Endocrinology (1978)[S]	1,635
Gastroenterology (1990)[S]	1,469
Hematology-oncology (1974)[S]	2,780
Hospice and palliative care (2008)[^]	234
Infectious disease (1994)[S]	1,432
Medical toxicology (1994)[S]	42
Neonatology-perinatal medicine (1975)[S]	5,930
Nephrology (1974)[S]	932
Neurodevelopmental disabilities (2001)[^]	255
Pulmonology (1986)[S]	1,203
Rheumatology (1992)[S]	364
Sleep medicine (2007)[^]	251
Sports medicine (1993)[^]	247
Transplant hepatology (2006)[^]	103

*Year in parentheses indicates when subspecialty board was established.
[S] = certificate of special qualifications
[^] = certificate of added qualifications
From American Board of Pediatrics 2014 Workforce Data: Pediaatric subspecialty Diplomates Certified Through December 31, 2014. Available at: www.abp.org/sites/abp/files/pdf/workforcebook.pdf. Accessed September 8, 2015.

The most common countries of citizenship for IMGs are (in rank order, 2007 data): United States (US citizens trained abroad), India, Philippines, Mexico, Pakistan, and the Dominican Republic. Resident and fellowship training of IMGs continues, although the percentage of first-year pediatric residents who were IMGs declined from 33% to 20% from 1991 to 2014. For fellowship, however, large numbers of subspecialty trainees are IMGs, notably in pulmonary disease (92%), nephrology (68%), and geriatric medicine (63%).

Hospitalists

The traditional American system in which primary care physicians have cared for their hospitalized patients is undergoing a dramatic change. The field of hospital medicine and the role of hospitalists have grown rapidly in the past decade, and hospital medicine has been the fastest growing field in pediatrics. Hospitalists replace primary care physicians in managing patients while in the hospital. Factors contributing to the growth of hospitalists' role include greater complexity of hospital care, need for greater efficiency in both outpatient and inpatient settings limiting the ability to do both, reduced work hours for trainees, and demand for attention to high-quality outcomes for hospitalized children. A 2009 survey by the Society of Hospital Medicine found that there are nearly 30,000 hospitalists in the United States, with an estimated 2,500 who focus exclusively on pediatrics. This represents rapid growth from 2002, when there were an estimated 600 pediatric hospitalists. In 2003, 40% of pediatricians were affiliated with a hospital that employed a hospitalist. This proportion is expected to continue to grow over the next several years.

Hospitalists are physicians whose main responsibility is the general medical care of hospitalized patients and whose responsibilities may also include teaching, research, and administrative duties. Pediatric hospitalists spend most of their clinical time on inpatient units, but not in the nursery, subspecialty units, or outpatient clinics. However, as with adult counterparts, pediatric hospitalists are taking on additional roles, including provision of newborn services, comanagement of surgical patients, and additional training and work in sedation and procedural roles. Hospitalists also seem to be effective teachers in academic centers. Patients are referred by primary care physicians and are referred back at the time of hospital discharge. The disadvantages of this arrangement include a loss of continuity of care between the primary care physician and the patient and a decreased scope of practice among general pediatricians. This requires careful attention to coordination of care and communication across the inpatient and outpatient domains. The use of hospitalists allows for increased productivity by the office-based pediatrician. During office hours, leaving the office with waiting patients to see a hospitalized patient is difficult for a physician. Other reported advantages of hospitalists include their competency in technical skills (skills easily lost to the physician who visits the hospital only occasionally), shorter patient hospital stays because of constant in-hospital supervision, and the immediate availability of urgent care. (See Chapter 9, Partnering With Families in Hospital and Community Settings, and Chapter 10, Family-Centered Care of Hospitalized Children.)

Nonphysician Clinicians

A large body of research evidence indicates that appropriately trained nonphysician clinicians—nurse practitioners and physician assistants—provide health care for many health conditions that is of equal quality to that provided by physicians. Because they can be trained at lower costs to society and their salaries are lower than those of physicians, many physician organizations and health maintenance organizations employ these professionals as primary care physicians and physician extenders in specialty settings. States are giving more independence to nonphysician clinicians. Restrictions on the work hours of resident physicians enacted in 2003 and updated in 2010 by the ACGME are another driver of the increasing role of nonphysician clinicians. In its official policy statement on nonphysicians in clinical care, the AAP states, "Pediatricians should respect the contributions of other health care professionals but also acknowledge the appropriate limitations and roles of these professionals." Further, "The AAP realizes that nurse practitioners, physician assistants, and other nonphysician

pediatric clinicians may care for children in underserved areas where patients have limited or no access to a physician. However, a pediatrician should oversee these clinicians."

Pediatric nurse practitioners (PNPs) are usually prepared at the master's degree level after training in nursing. Approximately 90% practice in primary care settings. A small share may be certified in a specialty, and recently there have been increases in those practicing in hospital settings. Outpatient PNPs conduct physical examinations, track medical histories, make diagnoses, treat minor illnesses and injuries, monitor chronic disease maintenance therapy, and provide an array of counseling and educational services. Inpatient PNPs are often found in intensive care units and emergency departments, although also in general medical and surgical units, and provide front-line care similar to resident physicians or hospitalists. In many states, PNPs prescribe medications independently, admit patients to hospitals, and make hospital rounds. As of 2008, there were 13,384 PNPs in the United States. Most PNPs worked in private practice (39%) or an academic medical center (25%). The remainder worked in community hospitals (14%), community clinics (10%), school-based health clinics (7%), managed care organizations (3%), retail-based or urgent care sites (1%), and nurse-managed centers (1%).

Physician assistants (PAs) are health care professionals licensed to practice medicine with physician supervision. Similar to nurse practitioners, PAs conduct physical examinations, diagnose and treat illnesses, order and interpret tests, write prescriptions, and counsel on preventive health care; they may also assist in surgery and in other procedures. Because of the close working relationship they have with physicians, PAs are educated in the medical model designed to complement physician training. The number of pediatric PAs is smaller but growing. In 2009, 2,144 pediatric PAs self-identified.

PROCESSES OF HEALTH CARE

The process of health care consists of the interactions between patients and professionals. From the physician's perspective, key processes include identification of and screening for new problems; patient education; matching appropriate services to a patient's needs; diagnosis using cognitive processes, laboratory testing, and imaging studies; treatment with watchful waiting, information giving and guidance, prescribing, and therapeutic procedures; follow-up of ongoing problems; referral to specialists and community resources; and admission to the hospital. From the patient and family's perspectives, the key processes of health care are seeking health care and choosing to use services, disclosing health-related information and asking questions, self-management for ongoing problems, participating in the recommended care plan, and assessing treatment effectiveness.

Scope of Pediatric Practice

The time a pediatrician spends in office practice remains challenging and interesting, although it is channeled differently than it was in the past. Through much of the early and middle 20th century, the practicing general pediatrician was the daily expert, always on call in the office for families in need or making frequent house calls and hospital rounds. General pediatricians dealt with all minor and most major illnesses. Pediatric subspecialists were few, usually found only in academic medical centers. Concepts such as *primary* and *tertiary* pediatric care were less known, and pediatric intensivists, neonatologists, and other subspecialists did not exist in community hospitals.

Today, the office-based primary care pediatrician practices differently, although still as the specialist providing medical care for children. The patient is almost always seen in the office, rarely in the hospital, and almost never in the home. The illnesses treated by the primary care pediatrician today do not resemble those of the past when serious infections and their sequelae were more common. Today, upper respiratory tract infections, moderate lower respiratory tract problems, feeding problems, gastrointestinal upsets, and minor trauma account for upward of 85% of illness care. Pediatricians evaluate and diagnose more serious conditions, coordinate and manage chronic illnesses, and collaborate with specialists on the care of children receiving such services. The primary care pediatrician spends more time on anticipatory guidance, including the promotion of health and well-being in children. A large portion of practice time is spent giving well-child care, dealing with family dynamics, and managing the new morbidities of mental illness, obesity, and school failure. Practices in urban areas deal with many of these issues with greater frequency and intensity. The new scope of contemporary pediatric primary care is summarized in Box 1-1.

Changes in how acute infections are managed or prevented will have important and perhaps even dramatic effects on the future scope of pediatric practice. National policy recommendations to decrease use of antibiotics for upper respiratory infections and otitis media have led to fewer prescriptions and visits for these conditions. New vaccines will further reduce the burden of acute illnesses in pediatric practice and could allow pediatricians to provide more comprehensive services to enhance child health and development; promote healthy transitions into school, adolescence, and adulthood; reduce the suffering associated with psychosocial problems; and collaborate with families to maximize the chances that all children become flourishing adults.

Referrals: Linking Primary Care With Specialty Care

Physicians providing primary pediatric health care assume responsibility for a broad spectrum of preventive and curative care and for coordinating the care their patients receive from other physicians. When primary care physicians need assistance in diagnosing and managing difficult cases, desire a specialized test or procedure (eg, endoscopy or surgery), or believe that management of their patients' health problems falls outside their scope of practice, they seek consultation and referral (See Chapter 6, Medical Home Collaborative Care). Approximately 2% of all general pediatric visits lead to a referral, and pediatricians make approximately 1 referral a day. Referrals are also

BOX 1-1 Scope of Pediatric Primary Care Practice

- Prenatal counseling to families preparing for the birth of their child
- Immunization for all age groups in the practice, with prior educational advice as to the benefit, risk, and alternatives
- Acute illness management, including watchful waiting, appropriate prescribing, education, and follow-up
- Injury prevention by giving advice about seat belts, smoke alarms, water safety, home safety, poison control, and bicycle helmets
- Minor injury treatment
- Coordinating services for children with complex medical needs
- Structuring the practice consistent with the principles of the medical home
- Collaborating with families to support the achievement of educational goals from infancy through adolescence
- Becoming an expert on violence prevention and abuse avoidance
- Providing advice and support during divorce, marital crises, or a loss of a family member
- Counseling families on lifestyle goals, such as the need for family time and for an understanding of work-related time constraints and stresses and how the family copes with them
- Promoting good health habits through advice about a prudent diet and nutrition, exercise, and dental hygiene
- Promoting avoidance of bad health habits such as sedentary activity, excessive television watching and video game playing, and parental smoking
- Identification and management of developmental and psychosocial problems, which is composed of screening, talk therapy, medication management, referral to and comanagement with behavioral health specialists, and linkage with appropriate community resources
- Encouraging community activism through knowledge and use of common resources and involvement with school boards, religious groups, school athletic programs, and community facilities
- Care of adolescents and young adults, with the twin goals of providing guidance and anticipating problems in areas such as sexuality, sexually transmitted infection avoidance, drug and alcohol abuse and teenage pregnancy prevention, and education and career goals advice
- Supporting families to ensure that all children become flourishing adults

made in telephone conversations with parents, which account for 25% of all referrals. For 75% of referrals, pediatricians anticipate sharing care with, not delegating care entirely to, the specialist; unfortunately, this practice is not often achieved, although delivery systems are finding ways to promote comanagement using an information technology platform or by locating generalists in specialty offices to evaluate and manage lower-acuity referrals.

The 15 most common health problems that general pediatricians refer to specialists and the types of specialists referred to for each problem are shown in Table 1-3. Most referrals are not for chronic diseases or for children with special health care needs but rather are made for time-limited musculoskeletal, skin, eye, or ear, nose, and throat problems. An important caveat is the large share of referrals for psychosocial and developmental problems, which, if combined, would be the most common reason for referral. Many specialties have overlapping scopes of practice, which is reflected in Table 1-3; for example, pediatricians send patients with hernias and hydroceles to both general surgeons and urologists. Why one type of specialist is selected rather than another is related to a pediatrician's personal preference and the relationships the primary care physician may have with specialist colleagues.

Among young children, an equal proportion of visits are made to pediatric subspecialists and non–pediatric-trained specialists. By adolescence, however, a greater share of visits occurs with specialists who are not trained as pediatricians. Pediatric societies have championed the notion that the specialty care of children and adolescents should be provided by pediatric-trained medical and surgical specialists. For example, the Surgical Advisory Panel of the AAP in 2002 asserted that all children 5 years or younger who require surgical care should be referred to a pediatric surgeon.

OUTCOMES OF CARE

The purpose of health care is not merely to build delivery systems or produce medical services. A society establishes a child health care system to improve children's health and well-being. Thus, the most important measures of pediatric health care effectiveness are related to the effect of services on child health and well-being. The claim that *children are healthy* is a myth that originates in the anachronistic notion of children as little adults. Pediatrics is clearly different from adult medicine, as articulated by the 4 unique characteristics of childhood: developmental change; dependency on parents and other adults for receiving health care; differential epidemiology of health, illness and disability; and demographic patterns that include high rates of poverty and single-parent families. Focusing on the word *healthy* in this context, if children are considered *little adults,* then their lower disease burden is certainly an indicator of better health. Only 10% of children have one of the long-term disorders—diabetes, cardiovascular disease, or asthma—that are typically included in disease-specific

Table 1-3 The 15 Most Common Health Problems General Pediatricians Refer to Specialists and Nonphysician Clinicians With Specialized Skills

HEALTH PROBLEM REFERRED	PERCENTAGE OF ALL REFERRALS MADE BY GENERAL PEDIATRICIANS	MOST COMMON TYPES OF SPECIALISTS REFERRED TO (PERCENTAGE OF TOTAL)
Otitis media	9.2	Otolaryngologist (95.3) Audiologist (3.5)
Refractive errors	5.6	Ophthalmologist (67.3) Optometrist (32.7)
Musculoskeletal signs and symptoms	5.0	Orthopedic surgeon (71.0) Physical therapist (11.8)
Benign skin lesions	4.5	Dermatologist (80.7) Plastic surgeon (10.8)
Behavioral problems	3.5	Psychologist (58.5) Psychiatrist (18.5)
Fractures (excluding hips and digits)	2.9	Orthopedic surgeon (92.5) Otolaryngologist (7.5)
Joint disorders, trauma related	2.7	Orthopedic surgeon (87.8) Physical therapist (12.2)
Developmental delay	2.6	Neurologist (20.8) Orthopedic surgeon (12.5)
Hearing loss	2.5	Audiologist (71.3) Otolaryngologist (28.3)
Strabismus, amblyopia	2.5	Ophthalmologist (97.8) Optometrist (2.2)
Viral warts and molluscum contagiosum	2.5	Dermatologist (87.0) Podiatrist (8.7)
External abdominal hernia and hydrocele	2.3	Pediatric or general surgeon (90.7) Urologist (9.3)
Depression and anxiety	2.3	Psychiatrist (52.4) Psychologist (40.4)
Allergies	2.1	Allergist (89.5) Ophthalmologist (5.3)
Chronic pharyngitis and tonsillitis	2.0	Otolaryngologist (94.6)

studies. Likewise, no more than 20% of children have a chronic physical, developmental, behavioral, or emotional condition that requires health and related services of a type or amount beyond that required by children generally. Less than half of these have conditions that affect a child's activities of daily living. The low prevalence of medical disorders calls into question the appropriateness for children of the conventional disease-oriented model of health. Certainly, a focus on children with chronic conditions merits continued attention. However, if improvement in the health and well-being of all children is the goal, then pediatrics must maintain an expanded conceptualization of child outcomes.

The developmental trajectories of childhood, which result from dynamic person-environment interactions, and the importance of the family to child outcomes are additional reasons that a child-specific outcomes framework is needed. Perspectives of health that incorporate a time dimension and the need to consider factors that threaten or promote future health are now encomposed in accepted definitions of health. Using this comprehensive concept of health, more than 50% of children have a significant need in terms of their well-being, symptom burden, risk behaviors, or psychosocial resilience. The time dimension of health suggests the need to focus attention on risks—health states and behaviors that are precursors to future morbidity, injury, and illness—as well as health promotive factors. Although the consequences of risks may not manifest until adulthood, antecedents to risk behaviors and states are molded during childhood, and many risk behaviors make their debut in adolescence. The weight-activity-nutrition complex illustrates this life course perspective. In childhood, the antecedents to obesity—eating and activity behaviors—are formed. By late middle childhood and early adolescence, approximately 1 in 6 individuals is overweight, with a heightened risk for future disease. For most individuals, the consequences of obesity—diabetes, asthma, low back pain, hypertension, and heart disease—do not become a problem until adulthood, although they occasionally appear in adolescence and even in childhood.

Promoting child health has intrinsic merit and has benefits for adulthood. Viewing health across the life span has been called the *life course model of health*. The model suggests that health is produced across the

life span, but childhood is a critical period. Unique person–environment interactions exist at each stage of development, some of which can have profound effects on future health. In addition, health care delivery must be considered in the framework of broader societal needs, such as improving the health of the whole population, enhancing patient experiences, and reducing (or at least controlling) per capita costs of care—aims the Institute for Healthcare Improvement calls the Triple Aim.

In summary, a framework for assessing the effects of health delivery systems on child outcomes must be specific to the unique needs and experiences of children, be developmentally sensitive, incorporate a time dimension, and be rooted in a life course model of health production. Table 1-4 provides such a framework, showing the key child outcome concepts and examples of specific metrics. Each of the 8 child outcome domains from Table 1-4 is discussed here, with special emphasis given to linkages with medical services.

Survival

The significant declines in mortality during the past century can be attributed more to improvements in public health than to specific technological advances applied to individual patients. The discovery of antibiotics was the most important scientific advance applied to individual patients that has had an impact on improving life span. The marked improvement in life expectancy over the last century has resulted primarily from lowered infant mortality. Infant mortality began to decline long before specific medical interventions were imposed, and the decline resulted from general improvements in sanitation, maternal nutrition, hygiene, and infant feeding. Immunizations are an important, although not singular, determinant of this decline. After infancy, deaths in childhood are so relatively infrequent that they are an insensitive indicator of the value of medical interventions. Some researchers have argued that disease-specific mortality statistics, such as 5-year cancer survival, are the most

Table 1-4 Child Outcomes Framework for Assessing the Effects of Health Care Delivery Systems, Organized by 8 Domains

OUTCOME	MEASURES (EXAMPLES)
SURVIVAL	• Infant mortality • Life expectancy • Five-year survival rates for specific diseases, such as cancer • Cause-specific mortality rate, such as mortality caused by asthma
INJURY AND DISEASE	
Injury	• Unintentional injuries • Intentional injuries • Child abuse and neglect rates • Suicide rates among youth
Development of disease	• Vaccine-preventable infections, such as measles, hepatitis B, pertussis • New cases of specific disorders, such as asthma, depression, attention deficit disorder, type 2 diabetes, seizure disorder, allergies, acne, metabolic syndrome, anxiety
Disease complications	• Severe dehydration • Suicide associated with depression • Iatrogenic complications associated with surgical interventions • Iatrogenic complications associated with medications • Consequences of untreated or inadequately treated infections, such as post-streptococcal glomerulonephritis, Lyme arthritis, pelvic inflammatory disease • School days lost resulting from illness
Disease severity	• Among patients with diabetes, glycated hemoglobin level • Among patients with asthma, forced expiratory volume in 1 second • Among children with hypertension, systolic and diastolic blood pressure levels • Cancer stage at diagnosis
GROWTH	• Birth weight • Underweight and failure to thrive • Overweight and obesity
FUNCTIONING AND DEVELOPMENT	
Mobility	• Attainment of age-appropriate mobility developmental milestones (eg, age child walked) • Days of restricted activity • Amount and frequency of physical activity

Continued

Table 1-4 Child Outcomes Framework for Assessing the Effects of Health Care Delivery Systems, Organized by 8 Domains—cont'd

OUTCOME	MEASURES (EXAMPLES)
Self-management	• Attainment of age-appropriate self-care developmental milestones (eg, getting dressed independently) • Sleep habits • Nutritional intake behaviors • Dental hygiene • Adherence to medication regimens
Communication	• Attainment of age-specific receptive language capacities • Attainment of age-specific expressive language capacities
Interpersonal interactions	• Developing satisfying and fulfilling friendships • For youth and young adults, developing intimate relationships
Intellectual performance	• School readiness • Academic performance, such as grades and grade completion • Graduation from secondary school
FAMILY	
Family impact	• Parental work days lost resulting from a child's illness • Parental worry about child's health
Family connectedness	• Parental time spent with children in activities such as play, recreation, meals • Quality and frequency of child–parent discussions about the child's life • Parental monitoring of children's activities within and outside the home • Parental monitoring of children's use of the media (TV, Internet, social networking)
RISKS	
Risk behaviors	• Tobacco smoking • Alcohol use • Drug use • Early sexual debut; unsafe sex practices • Not wearing a seat belt while riding in a motor vehicle • Not using a helmet while riding a bicycle
SYMPTOMS AND COMFORT	
Symptoms	• Physically experienced sensations, feelings, and perceptions that are the result of a disease process • Emotionally experienced sensations, feelings, and perceptions that are the result of a disease process
Comfort	• Physically experienced body sensations, feelings, and perceptions that are not associated with a known disease process • Emotionally experienced body sensations, feelings, and perceptions that are not associated with a known disease process
WELL-BEING	• Happiness • Self-worth • Life satisfaction • Meaning and purpose

compelling mortality statistics to use to assess system effectiveness because they are directly related to the adequacy of treatment.

Disease and Injury Prevention

Even though pediatricians may not be able to prevent the occurrence of most disorders, they should be expert at recognizing these problems when they occur. The application of diagnostic or therapeutic strategies requires first that problems, or potential problems, be recognized. Evidence indicates that the existence of many types of health problems is often overlooked. For example, physicians are consistently poorer at recognizing the existence of behavior problems and social factors related to illness than they are at recognizing problems that have obvious biophysiologic or anatomic manifestations, even though these factors have profound influences on health and well-being. However, even organic problems may be neglected. Problem recognition also extends to prevention of disease.

One type of prevention, *primary prevention,* is traditional to pediatricians. It consists of recognizing susceptibility to disease and applying interventions to prevent disease from occurring. Although immunizations are the most obvious example of primary

prevention, prevention goes far beyond this measure. In some instances, only certain people are at risk for acquiring disease later in life; pediatricians must direct efforts at discovering who these people are, keeping them under surveillance, and trying to eliminate the situations that allow the illness to develop. This approach is known as *secondary prevention*, which is aimed at identifying disease in early stages before it causes significant morbidity. Secondary prevention occurs at the physician–patient level, as well as through the initiatives of government and social agencies. Examples of such efforts include hearing and vision screening in schools, screening programs for specific disease in special populations (eg, sickle cell anemia), and state-mandated neonatal screening for inherited metabolic disorders (eg, phenylketonuria). Newer prevention challenges for pediatricians concern recognizing and dealing with occupational hazards that result in parents unknowingly exposing their children to toxic materials invisibly carried home from the workplace. As social, occupational, environmental, and behavioral factors become recognized as important antecedents of many chronic illnesses, pediatricians will become more involved in activities directed toward preventing them.

Much of health care is devoted to minimizing the effect of diseases on health, which is *tertiary prevention*. Reducing the impact of injury by limiting the duration of disability is an outcome that health care delivery systems can affect, although the provision of health services is not the only determinant of functional recovery. Similarly, health care attempts to prevent or mitigate the effects of disease complications and to stabilize the disease itself so as to reduce its severity. Because managing the complexity, stability, and complications of disease is a common and effective part of pediatric practice, indicators of the adequacy of disease control are obvious candidates for outcomes for which the health care delivery system should be accountable.

Growth

Monitoring children's growth is one of the cornerstones of pediatric primary care. Assessing growth requires pediatricians to examine both tails of the distribution, underweight and overweight, and linear growth. The ability of pediatricians to identify growth problems is well established. Whether pediatric professionals have an important effect on preventing growth problems is less clear. Today, approximately 17% of children are obese. Interventions that pediatricians can apply to prevent the problem of obesity are lacking. Problems with inadequate weight are more easily addressed by health care; however, the degree to which a health care delivery system can affect the healthy growth of an entire population remains to be demonstrated. (See Chapter 298, Obesity and Metabolic Syndrome.)

Functioning and Development

Children's functional capacities in the areas of self-management, mobility, communication, interpersonal interactions, and intellectual capacity rapidly change, and acquisition of new abilities characterizes stages of development; they are also targets of health services. Monitoring age-appropriate development of new capacities and intervening with children who have problems in each dimension are a fundamental part of well-child care. Increasing attention to early brain and child development, as well as reducing toxic stress, in the first 3 years of life holds great promise for reducing learning and behavior problems in school-aged children and adolescents.

Reducing the number of days of restricted activity, for example, because of acute illness or asthma is often a primary treatment outcome. When asked about the meaning of *being healthy,* children and youth talk about "being able to do what I want to do, play what I want to play, or see my friends." Similarly, children know that healthful self-management habits are an important part of their health status, and counseling on these topics is part of virtually every routine health visit. One of the new morbidities with which pediatricians have become more concerned is learning and intellectual development. For young children, pediatricians counsel parents about the importance of reading to brain development, enjoyment, and being prepared to learn once the child starts school. Programs such as Reach Out and Read (www.reachoutandread.org) have been developed to provide office-based physicians with tools for promoting early childhood literacy.

As children get older, pediatricians work with them and their families in setting educational goals, monitoring children's performance in school, and, with youth, setting goals for their young adult professional lives. Perhaps the single best indicator of the health of a population of children and youth is the rate of graduation from secondary school. Healthy children finish high school and successfully transition into adulthood.

Family

Children's health outcomes are inextricably bound with their family. The family and home life are the most important contexts in the production of children's health and for promoting their development. Parenting and family involvement in a child's life are especially critical. A variety of studies have shown that accumulated childhood exposures to different types of abuse or household dysfunction directly increase the risk for psychiatric disorder and several chronic diseases that emerge later in life. Abuse appears to alter the structures and functions of a child's brain and the body's reactivity to stress. Unstable (especially rejecting) parent–child relationships produce biological changes that interact with future environmental stimuli to produce adult disease.

Child health can affect the family by influencing parental emotions and mood (eg, excessive worry about a sick child, a depressed mood in a parent who devotes a large share of time to the care of a child with a special health care need) and parents' work productivity. These family outcomes can then affect children's health in a reciprocal dynamic relationship.

Risks

When a child or youth engages in high-risk behavior, the chances of future injury or disease are increased. Not wearing a helmet while riding a bike enhances the likelihood that if the child is in a bike accident, a head injury will occur. Tobacco smoking in adolescence negatively affects pulmonary function and begins a cascade of negative effects on future cardiovascular and pulmonary structure and function. Early sexual debut heightens the chances for acquiring sexually transmitted infections and teen pregnancy. Inappropriate exposures to smoking, sex, and violence in the media, on the Internet, and via social networking all increase the likelihood of risky behavior in adolescents.

Routine health visits for adolescents should always address risk avoidance. Significant effects of these interventions, primarily information giving and counseling, on the incidence and frequency of risk behaviors have not been shown in research studies. This type of evidence is needed to guide risk avoidance interventions better. Until these data are made available, most professionals would not want to be held accountable for the levels of risk behavior in the population for whom they care.

Symptoms and Comfort

Feelings of discomfort can be experienced physically and emotionally, and they may or may not be linked to a disease. Almost one-half of all office-based visits involve some degree of symptom management. Children who feel uncomfortable are less involved in desired activities, more likely to miss school, and more unhappy than others without the same feelings. Relieving the suffering associated with illness is a core function of health services delivery. Thus the level of comfort of a patient population or the symptom burden of a diseased subgroup is a clear outcome indicator that can be linked to health services.

Well-Being

Well-being has 2 components. The first component, simply stated, is happiness—the degree to which life experiences match the individual's expectations. Health care delivery systems add to the happiness of children by ensuring that the risk of injury and disease is as low as possible and the impact of disorders when injury or disease occurs is minimized by preventing unwanted symptoms and ensuring the highest level of comfort possible, by promoting growth and development, by counseling on behavior (both ways to improve health directly and ways to avoid harm), and by supporting families in the care of their children.

The second component is meaning, predictability, and flourishing. Healthy children see and plan for their future. Children who have led healthy lives are more likely to become flourishing adults.

Outcomes and Health Services

Some outcomes Table 1-4 are more amenable to health care services than others. The knowledge base linking services to outcomes is largest for the biological outcomes of survival, disease, and growth. The fact that many commonly applied therapeutic maneuvers are of unproved usefulness and may even be dangerous is well known. For example, several studies demonstrate that surgical rates in the United States are much higher than those in other developed countries, without any demonstrable difference in the need for surgery as defined by prevalence of disease or illness. Even within the United States, the number of hospital admissions, the length of stay in the hospital, and the rate of surgical procedures vary markedly from area to area, unrelated to differences in medical need—although socioeconomic circumstances may be a component of this variation. This potential overuse of specialized services might actually result in poorer outcomes, with more patients than necessary experiencing iatrogenic complications of interventions. Another problem is the misuse of drug therapy. Outcomes data will be helpful in determining the usefulness of various therapeutic maneuvers and will guide the appropriate use of drugs. In a related way, prescribing medications or home-based management strategies that are not adhered to by patients or families is an important challenge to the ongoing care of illness. Nonadherence is costly and can result in unnecessary escalation of therapy or hospitalization for exacerbation that could have been prevented (eg, asthma). As the demand to connect outcomes to process grows, the likely scenario is that physicians will be encouraged, and perhaps even required, to keep certain types of data about children in their practices. A data set for hospitals to use for each patient admitted and a similar set for ambulatory care have been accepted by the National Center for Health Statistics and recommended for wide use. This information includes registration data (patient identification number, name, address, birth date, gender, race, and marital status) and encounter data (facility identification number, provider identification number, patient identification number, source of payment, date of encounter, patient's purpose for visit, physician's diagnosis, diagnostic and management procedures, and disposition). Adoption of this or a similar system for collecting and standardizing information will facilitate the understanding of health and disease processes and the role medical care plays in influencing them. (For more details, see Chapter 5, Quality Improvement in Practice.)

To ensure that diagnostic procedures and instituted therapy are adequate and that problems are being resolved as expected, patients must be monitored; this approach is known as *outcomes assessment*. Medical textbooks and teaching rarely include information that helps the physician define appropriate intervals for reassessing particular health problems. Such information has to come from careful studies of the natural history of patients' problems, with and without intervention, and such studies are rare. Moreover, little is known about the extent to which physicians follow up with problems they treat. When the issue has been examined, research shows that failure to follow up on treated patients results in unresolved health problems; at the very least, it produces a highly inefficient health care system: Care is paid for, but no benefit is gained. At the most, outcomes assessment will ultimately lead to societal demands for greater

accountability of the profession. Fortunately, careful review and analysis of publications on the diagnosis and treatment of illness has led to the development of evidence-based guidelines, which, when used, are expected to improve health outcomes. Yet, no consensus exists on the specific outcome metrics by which the effectiveness of health care delivery systems should be evaluated. For which outcomes should health care delivery systems be held fully accountable, partially accountable, or not at all accountable? This question remains largely unanswered, which severely limits the profession's ability to use outcomes assessment to improve health care services. Future health care delivery systems for children must become more outcomes oriented. Deciding on which outcomes to base these new delivery systems is an urgent task facing all child health care professionals and managers.

TOOLS FOR PRACTICE

Community Advocacy and Coordination

- *The AAP Child Health Mapping Project* (interactive tool), American Academy of Pediatrics and Dartmouth Medical School, Center for Evaluative Clinical Sciences (www.aap.org/mapping)

Engaging Patient and Family

- *Pediatric Specialists* (Web page), American Academy of Pediatrics (www.healthychildren.org/English/family-life/health-management/pediatric-specialists/Pages/default.aspx)

Practice Management and Care Coordination

- *Addressing Mental Health Concerns in Primary Care: A Clinician's Toolkit* (CD-ROM), American Academy of Pediatrics (shop.aap.org)
- *American Telemedicine Association* (Web site), (www.americantelemed.org/home)
- *Pediatric Call Centers and the Practice of Telephone Triage and Advice: Critical Success Factors* (report), American Academy of Pediatrics (www.aap.org/sections/telecare/11_98.pdf)
- *Pediatric Telehealth Care* (Web page), American Academy of Pediatrics (www2.aap.org/sections/telecare/default.cfm)
- *Pediatric Telephone Protocols,* 14th ed (book), American Academy of Pediatrics, Schmitt BD (shop.aap.org)
- *Practice Transformation* (Web page), American Academy of Pediatrics (www.aap.org/en-us/professional-resources/practice-support/Pages/Practice-Support.aspx)

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Chapter 2

PRACTICE ORGANIZATION

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The organization of the practice is critical for the primary care physician's success in providing high-quality care within a medical home and implementing and maintaining sound business principles. A study of 44 private pediatric and family medicine practices in North Carolina shows that low levels of preventive service performance and a significant percentage of bankruptcies were largely a result of poor organizational characteristics. A well-organized practice can meet the demands of patients, families, and payers for high-quality, cost-effective care by developing positive attributes in 4 major areas: (1) culture, (2) recruitment and retention, (3) defining and achieving goals, and (4) planning.

CULTURE OF A PRACTICE

The culture of a practice is the subjective feeling of the physicians, staff, and patients and their families about what it is like to work in and visit the practice. Is the atmosphere pleasant, friendly, caring, and supportive? Is it just the opposite? Or is it somewhere in between? The culture of the practice is set by the physicians, the natural leaders of the practice. Their attitudes and beliefs are often mirrored by the practice staff. Projecting a positive image is the responsibility of all staff, including nurses, receptionists, and administrators, but the physicians set the tone for providing

compassionate, family-centered care. First and foremost, physicians in well-organized practices believe that caring for children and working with their parents/guardians to achieve the best possible health outcomes for their children is a special privilege. Acknowledging and respecting the patient's and family's individual beliefs and customs are essential in providing comprehensive, culturally effective care. Pre-visit and follow-up patient communication and comprehensive office visits are seen as welcome opportunities to achieve these goals. Admittedly, sometimes on particularly busy days, maintaining this positive attitude can be difficult, but doing so is most important, lest a negative attitude be projected toward patients and parents by the physicians or staff. Increasingly, physicians recognize that patient- and family-centered care leads to optimal care and patient, family, physician, and staff satisfaction. By forming true partnerships with patients and families and practicing shared decision making between families and physicians and the care team, pediatricians develop a better understanding of the patient's/family's goals and increase the likelihood of a mutually agreed-upon management plan and better compliance with that plan.

Mutual respect is a fundamental characteristic of a well-organized practice. All members of the practice must treat each other with courtesy and dignity at all times, avoiding negative remarks or comments. If someone in the practice shows a need for improvement, then this need should be discussed with the individual privately in a positive fashion. Creating a respectful atmosphere in the practice is highly beneficial for staff performance and families' perception of the practice.

Teamwork provides the basis for a high-functioning medical home. Delivering high-quality care is a complex process requiring the coordinated efforts of physicians, nurses, receptionists, and administrative personnel. All activities must be coordinated to develop a well-functioning team with clearly defined roles and responsibilities and a seamless system of transition among the staff. This is particularly important when patients are transferred from one physician to another at the end of a session or day. One way of ensuring that all the pertinent information about the patient is appropriately communicated is to use the acronym DATAS:

Descriptive identification of the patient
Active patient issues
To do—follow-up issues
Anticipate potential problems and interventions
Special instructions

Finally, notably, a well-organized practice functions in a democratic fashion rather than an authoritarian one. It is important to define practice governance so each individual knows to whom they directly report and who should hear their ideas or concerns. Decisions regarding practice policies, goals, and activities are reached by a thorough discussion with all members of the practice, hopefully leading to consensus so that all staff members are invested in the decisions that are made. This process requires physicians and staff to listen respectfully and with an open mind to everyone's opinions and to encourage frank discussion regarding potential solutions to problems and challenges. Patients and families should also be able to contribute their ideas for practice improvement, whether through a suggestion box, family advisory group, or other venue. Ultimately, the practice needs an identified individual physician or group who is empowered to make final decisions in the best interest of its patients, families, employees, and fiscal viability. The pediatrician managing partner has the ultimate responsibility for making decisions about the conduct of the practice. Often, she or he may be assisted by a planning or executive committee of physicians, nurses, staff, and parents.

A mission statement that reflects the individual values of the care team can be a useful tool to clearly define priorities of the practice and establish a positive culture within the family-centered medical home.

RECRUITMENT AND RETENTION

Recruitment of high-quality physicians, nurses, and medical assistants, nonclinical staff, and administrators into the pediatric practice is an important goal for a well-organized practice. However, recruitment is only one half of the equation, with retention of valued employees forming the other half. Given that orientation of new staff members to their functions within the practice can be disruptive, time-consuming, and expensive, high turnover rates are to be avoided. Furthermore, patients and families greatly appreciate hearing a familiar voice or seeing a familiar face in their interactions with the practice. Additionally, long-term staff members gain an understanding of patient and family characteristics that can be particularly helpful in providing care for those patients and families. Finally, physicians and staff develop efficient patterns of interaction with each other over time, and regular staff meetings where opinions are addressed and valued greatly improve the overall functioning of the practice. Thus taking the appropriate measures necessary to retain a high-quality staff is in the pediatrician's best interests.

Developing positions of responsibility within the care team can be beneficial in providing a high-quality medical home. It is important to establish a designated care coordinator whose role goes beyond coordinating a patient's medical care, and includes engaging other resources in the community to support the growth and development of the child. Assigning tasks and responsibilities to other staff members such as asthma coordinator, newborn-screening coordinator, and lab coordinator, as well as bringing in ancillary staff such as nutritionists, psychologists, therapists, and lactation consultants, helps to round out the comprehensive-care team. Designating clear roles and responsibilities to members of the care team acknowledges their importance and improves efficiency, satisfaction, and clinical outcomes.

Continuing education is a critical component to staff retention and satisfaction and can be incorporated into practice routines. Clinical education can be done while in the process of care or in more didactic sessions. A "lunch and learn" program encourages staff collegiality and increases their knowledge base.

Competitive salaries and benefits (health, life, and disability insurance and retirement plans) are essential to recruiting and retaining high-quality physicians and employees. Appropriate salaries and benefits should

be regarded as investments in high-performing individuals that will provide a substantial return on investment to the practice.

Financial rewards are obviously effective, but other techniques can be quite helpful as well. For example, frequent (daily) praise and appreciation provides employees with a sense of well-being and value. In addition, letting the staff know the outcomes of patients of concern with whom they have interacted will give them a sense of true investment in the care of the patient. Other methods of rewarding staff include occasional gifts to thank them for exemplary service during particularly stressful times. Finally, including all staff members in celebrations of such events as the achievment of major practice goals, the arrival of any new physician or staff member, 25th anniversaries, holiday parties, or retirements will let staff members know their value in the practice.

DEFINING AND ACHIEVING GOALS

The 2 major goals of a well-organized practice are providing high-quality care for its patients and families and implementing and maintaining sound business principles for financial success. Providing high-quality care requires more than well-trained physicians and staff. The practice needs to develop systems of care and daily work-flow processes designed to achieve the best practice results. Both the Institute of Medicine and the Institute for Healthcare Improvement have called for the implementation of appropriate systems of care at all levels in the medical-care spectrum. The systems-of-care principles are taken from those developed by the manufacturing industry and have been demonstrated to reduce variation and improve product quality. Many of these principles are applicable to medical practice and have been shown to improve outcomes significantly. One of the most important systems-of-care principles is measurement. Randolph and his colleagues show that some practices that measured immunization rates found that these rates were significantly lower than the physicians' estimates. The common business saying, "you can't manage what you don't measure" is applicable to pediatric practices. Pediatric practices should institute a host of measurement processes such as immunization registries, appointments-kept ratios, waiting time for appointments, and time taken to answer telephone calls, among other processes. See Chapter 5, Quality Improvement in Pediatric Primary Care, for detailed information on small cycles of improvement necessary for quality improvement.

Dedication to practicing evidence-based medicine for patients promotes safety and ensures a practice's committment to lifelong learning and continuous quality improvement. As part of this process, physicians need to be aware of the latest guidelines for care as published by the American Academy of Pediatrics (AAP) and other organizations and to work to institute these guidelines as a regular part of their practice. Essential to the quality improvement process are regular meetings of the physicians and staff to determine best how to put in place systems of care necessary to ensure high-quality outcomes. Finally, a well-organized pediatric practice must assess patient and family satisfaction and work toward improving staff members' performance in this area that will become increasingly important as patients and families have more incentive to seek out high-quality care with newer health insurance products. Thus listening to and acting on patient concerns and complaints, and surveying patients regularly to assess their satisfaction, are important activities. In addition, the practice should solicit patient and family feedback periodically in the form of patient surveys or a family advisory council. Such a council can consist of patients and parents who meet regularly (eg, 4 to 6 times per year) with physicians, nurses, and staff members to discuss ways to improve services for patients and families. The one constant in life is change. Defining and engaging in a continuous quality improvement process is essential in allowing a practice to meet the ever changing needs of its patients and families.

Given that the primary care practice of pediatrics is a business, sound business principles are required for practices to perform well financially. Because providing direct patient care is the primary revenue stream for most practices, the physicians themselves must maximize their time in clinical care; business management may be better handled by specifically trained employees. Practice policy development, adherence to legal regulations of governing bodies (OSHA, HIPAA, CLIA), and contract negotiations with insurers are critical areas where physicians should seek the advice or help of high-quality professional consultants. Practice clinical policy manuals, telephone advice instructions, and employee manuals should be used regularly and updated frequently. Experts in medical legal matters should be employed to assist with contracts and negotiation and to provide suggestions to reduce the risk of medical malpractice suits. Accountants with specific knowledge of medical economics should review the practice's financial accounts regularly and provide advice to improve financial performance. Similarly, management consultants with experience in medical-practice management should be consulted for advice in the structure of the practice. For practices of 3 to 5 physicians, an office manager with expertise in the business aspects of running a medical practice should be employed. In many cases, someone with a master's degree in business administration will be more effective than someone with less training. For practices of 6 or more physicians, a well-qualified and experienced practice administrator should be hired to oversee the complex operations of large practices. Although well-trained individuals may be expensive, they will usually return their salary many times over and should therefore be considered as an investment rather than an expense. In addition to an office manager, one or more of the physicians in the practice need to serve as managing partners, often overseeing a particular aspect of practice management such as personnel, financial performance, or quality improvement. Practices also should benchmark their performance financially by comparing their revenues and expenses to the performances of the best practices of similar size. Finally, attention to detail is absolutely required to ensure that the services provided are appropriately coded and billed for, all charges are captured, and collections are tracked carefully and maximized.

The AAP Section on Administration and Practice Management (SOAPM) has used the services of the Medical Group Management Association to survey pediatric practices and provides the results of these surveys on its Web site (www.aap.org/practicesupport). At least one pediatrician in the practice, preferably the managing partner, should be a member of SOAPM, keep up with the SOAPM list serve, utilize Practice Support frequently, and review the work of the AAP Private Payer Advocacy Advisory Committee (PPAAC) recommendations to learn the latest developments in the business of pediatrics and for helpful discussions on practice management. SOAPM, Practice Support, and the PPAAC are valuable benefits of AAP membership.

The use of computers in the well-organized pediatric practice is increasingly essential. Computerized billing systems have long been the norm for pediatric practices, and their hardware and software systems should be periodically upgraded to meet the demands imposed by an increasingly complex health-insurance system. Consultants are available either locally or nationally who can be of great assistance in purchasing the right computerized system for the practice. Beyond this effort, computerized or electronic medical records (EMRs) are becoming essential to provide high-quality care in the framework of a medical home (see Chapter 3, Information Systems in Pediatric Practice). The benefits of electronic medical records in providing reminder recall systems, improving immunization rates, and notifying patients and families of the recommended frequency of health assessment visits to care for children with chronic illnesses, to alert physicians regarding patients' allergic reactions to drugs, and to prevent drug–drug interactions have been well documented. Although these systems are quite expensive in terms of actual cost and the expense entailed in converting from paper records to EMRs, the benefits to patients and families and the reduction in personnel expenses for filing and transcribing justify the investment. Of course, installing an EMR system is essential to being able to provide patients and their families with a personal health record (PHR). For the latest information regarding EMRs, physicians should visit the AAP Council on Clinical Information Technology (COCIT) Web site (www2.aap.org/informatics/COCIT.html).

PLANNING

Another key element in determining the success of a business is planning for the future. Thus a well-organized practice will hold annual retreats to assess past progress, survey the local and national medical environmental trends, and develop a set of goals and measurable objectives for the next year. Preparation for this retreat should include a strengths, weaknesses, opportunities, and threats (SWOT) analysis, with particular attention paid to anticipated changes in health care financing (eg, new payment models or an increase in the number of patients moving to consumer-driven health plans), emerging changes in the structure of delivering primary care from privately operated pediatric practices to multi-site organizations to larger integrated health systems and accountable care organizations, birth rates, child health disparities, population changes, and physician supply changes. The practice should formulate a strategic plan for the coming year and review the plan every quarter to determine progress toward the goals and objectives. Hiring a professional facilitator to assist in the retreat activities may be worth the investment.

CONCLUSION

Developing and maintaining a well-organized pediatric practice requires hard work, constant attention, and skills that are not usually taught in medical school or residency. However, physicians must devote the time and effort and acquire the necessary skills if they are to provide high-quality care in the context of the medical home model for patients and families and to be successful financially. A practice must have a commitment to quality improvement and be open to transformation in order to respond to the changing health care landscape and provide the highest-quality care to patients and families. The AAP and other professional societies offer courses in practice management. In addition, the AAP offers practice-management resources and tools on its Web site (www.aap.org/practicesupport). Running a successful practice can be challenging, but the rewards are well worth the effort.

TOOLS FOR PRACTICE

Community Coordination and Advocacy

- *A Checklist for Attitudes About Patients and Families as Advisors* (questionnaire), Institute for Patient- and Family-centered Care (www.ipfcc.org/advance/Checklist_for_Attitudes.pdf)
- *Creating Patient and Family Advisory Councils* (booklet), Institute for Patient- and Family-centered Care (www.ipfcc.org/advance/Advisory_Councils.pdf)
- *Culturally Effective Care Toolkit: What Is Culturally Effective Pediatric Care?* (Web page), American Academy of Pediatrics (www.aap.org/en-us/professional-resources/practice-support/Patient-Management/Pages/Culturally-Effective-Care-Toolkit.aspx)
- *Healthy People 2020 Program Planning* (Web page), US Department of Health and Human Services (www.healthypeople.gov/2020/tools-and-resources/Program-Planning)

Medical Decision Support

- *EQIPP* (online program), American Academy of Pediatrics (eqipp.aap.org)

Practice Management and Care Coordination

- *Family Centered Care Self-Assessment Tool,* Family Voices (www.familyvoices.org/admin/work_family_centered/files/fcca_FamilyTool.pdf)
- *Measuring Medical Homes: Tools to Evaluate the Pediatric Patient- and Family-Centered Medical Home* (monograph), National Center for Medical Home Implementation (medicalhomeinfo.aap.org/tools-resources/Documents/Monograph_FINAL_Sept2010.pdf)
- *Patient- and Family-Centered Ambulatory Care: a Checklist* (fact sheet), Institute for Patient- and Family-Centered Care (www.ipfcc.org/advance/topics/Ambulatory-Care-Key-Concepts.pdf)
- *Practice Transformation* (Web page), American Academy of Pediatrics (www.aap.org/practicesupport)

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Chapter 3

INFORMATION SYSTEMS IN PEDIATRIC PRACTICE

S. Andrew Spooner, MD, MS

INTRODUCTION

Fundamental to a functional medical home for children is an information system that supports a comprehensive, longitudinal record for each child and the ability to manage patient populations. The growing popularity of the Patient-Centered Medical Home (PCMH) program from the National Council for Quality Assurance formalizes one definition of the medical home and outlines the information management activities that a recognized practice should master. Although the PCMH program does not, strictly speaking, require an electronic health record (EHR), many of the activities specified in the program would be difficult to perform on paper. Table 3-1 outlines the main areas of functionality for the 2014 PCMH recognition program, along with examples of EHR functions that could help perform these activities efficiently.

During the past decade, physician practices and hospitals have spent an increasing amount of time and money on EHR systems. The rapid rise in the use of EHRs has been partly a response to the American public's long-standing call for better information management in health care, echoed by US presidents and codified in federal regulations as the Meaningful Use (MU) program and supported by patient perceptions of care quality. Adoption has been rapid, at least for basic EHR systems, but the barriers of complexity and cost mean that it will be many years before health care is completely paperless. Fortunately, the EHR market is responding to the need for systems that work for child health care, allowing pediatricians to adopt these systems, albeit at a slower pace. Only a minority of pediatric physicians use EHR systems that possess the full range of functionality. Although MU incentive payments reduce the net cost of implementation, questions remain about how to select a system, manage the change, and bear the total expense.

DEFINITIONS

Electronic Health Record Versus Electronic Medical Record

The Institute of Medicine defines an EHR system:

> An EHR system includes (1) longitudinal collection of electronic health information for and about persons, where health information is defined as information pertaining to the health of an individual or health care provided to an individual; (2) immediate electronic access to person- and population-level information by authorized, and only authorized, users; (3) provision of knowledge and decision-support that enhance the quality, safety, and efficiency of patient care; and (4) support of efficient processes for health care delivery. Critical building blocks of an EHR system are the electronic health records (EHR) maintained by providers . . . and by individuals (also called personal health records).

In this chapter, the term *EHR* refers to the system a physician would use in an ambulatory or inpatient setting to implement the primary and specialty care of infants, children, and adolescents. There is an older term, electronic medical record (EMR), that is often also used to describe these systems. The US Office of the National Coordinator for Health Information Technology makes the distinction that an EHR contains information aggregated from *all* physicians involved in a patient's care—not just from the physician who purchased the computer system. Although this may be a useful distinction, the reality in the marketplace today is that all vendors who sell EMRs call them EHRs, so that term will be used in this chapter.

Table 3-1 Patient-Centered Medical Home Standard (2014) and Examples of Supportive Electronic Health Record Functionality

Patient-centered access	Provide online access to medical record information. Support secure electronic messaging with patients.
Team-based care	Calculate proportion of encounters held with patient's personal physician. Maintain a written transition plan from pediatric to adult care.
Population health management	Record family history as structured data. Record social or cultural needs in health assessment. Create lists of patients who need preventive care.
Care management and support	Identify children and adolescents with special health care needs or high-cost utilization. Identify patients based on social determinants of health. Maintain individual care plans.
Care coordination and care transitions	Record laboratory and radiology orders. Track overdue laboratory results. Report on percentage of patients identified as needing care management.
Performance measurement and quality improvement	Report on 2 measures related to care coordination. Exchange data bidirectionally with a health information exchange.

Meaningful Use

The major driver of EHR design in the United States since 2009 has been the MU incentive program, a part of the Health Information Technology for Economic and Clinical Health (HITECH) Act of the American Recovery and Reinvestment Act of 2009. HITECH was intended to stimulate the adoption of EHR software, but the legislation was careful to define what sort of system could be called an EHR and what sort of uses of the system would qualify as *meaningful*. The motivation for creation of a definition of MU was to ensure that physicians would implement systems that had some benefits for patients and would enhance their ability to study care, to empower individuals, and to improve health outcomes. To ensure that EHR systems met the definition, a certification program was established in which software was required to demonstrate certain functions to become certified for the purpose of the MU incentive program. There was never any intent in the certification criteria to ensure that every EHR was appropriate for child health, but there are a few criteria that do help in this regard. For example, the criteria require that the system have growth charts and be able to communicate with immunization registries. Although promising, these requirements fall short of what most pediatricians would consider adequate. For instance, the growth chart requirement omits head circumference charts. Other gaps include omission of head circumference from the vital signs criterion, omission of a requirement for weight-based dose calculations in prescribing, and omission of passive smoking (or other forms of tobacco exposure important in pediatrics) in the tobacco history criterion. There are some other criteria that do meet some needs in child health, but a system that adheres to all the criteria for certification would not necessarily be rich in child health functionality as specified by the literature.

ELECTRONIC HEALTH RECORD SYSTEM AND CHILD HEALTH

Not all certified EHRs support all the published child health functions, and not all EHR systems are designed for pediatric care, so the pediatrician should examine carefully the capabilities of any system intended for use in a practice serving infants, children, and adolescents. In advocating for the inclusion of EHR functionality that supports important pediatric work flows, pediatricians should point out that most functions important in pediatric care are also useful outside of pediatric care. For example, drug dosing by body weight is critical in pediatrics, but has enough usefulness in geriatric care that it would also be desirable in nonpediatric systems. Likewise, weight and height monitoring have application in adult care. The ability to record guardianship status and accommodate proxy access is important in the care of adults with diminished capacity. Table 3-2 lists questions one might ask in the evaluation of the suitability of a system for a child health environment.

Table 3-2 Pediatric Functions of an Electronic Health Record With Questions to Ask About Electronic Health Record Functionality

FUNCTIONAL AREA	QUESTIONS TO ASK
Growth monitoring	Can the system plot growth data (height, weight, head circumference) over time and allow simultaneous comparison to normative curves? Does it include normative curves for special populations seen by the practice? Does the system plot BMI against appropriate normative curves of percentiles? Does the system indicate abnormalities in growth parameters (eg, flagging any weight below a certain percentile value or a BMI above a certain percentile)? Does the display of growth data allow magnification *(zooming)* of the display when examining densely packed data points? Does the system indicate corrections for prematurity on growth charts? Can the pediatrician note events such as Tanner staging, bone age determinations, or growth-arresting therapeutic episodes on the growth chart? Does the system allow printouts of the growth curves for parents? Is the growth chart viewable in the patient portal?
Immunization management	Does the system have active interfaces to any state immunization registries? If so, what is required to bring those interfaces live in the current practice? Can the system analyze a record of immunizations and recommend what immunizations are due at the time of the current encounter? At a designated future encounter? Can the system analyze a record of immunizations and indicate when the next immunizations are due? Are physicians alerted to this fact when the patient presents for care? Can the system store lot numbers and the versions of vaccine information provided for new immunizations? Can the system incorporate data indicating that a given series of immunizations is complete without having to manually enter the data on individual immunizations administered in the past? If so, is this information on series completion incorporated appropriately into decision support functions? Can the system print paper immunization forms for school entry based on data in the patient's record?

Table 3-2 Pediatric Functions of an Electronic Health Record With Questions to Ask About Electronic Health Record Functionality—cont'd

FUNCTIONAL AREA	QUESTIONS TO ASK
Medication prescribing	Does the system suggest a drug dose based on actual body weight? On age? On gestational age? Does the system allow dosing based on a *dosing weight* rather than actual body weight? Does the system display current body weight in the same view in which the user is expected to create prescriptions? If a non-weight-based dose is entered, does the system check drug doses for appropriateness based on body weight? Does the system support indication-specific dose ranges for a given medication? Does the system round the dose to a dose that is easily measured by parents (eg, 3 mL vs 2.8 mL, or ½ tablet vs 0.45 tablet)? Does the system alert the user regarding allergies to medications and possible adverse drug-drug interactions? In the case of controlled substances for behavioral disorders, does the system allow the user to authorize recurrent monthly prescriptions in accordance with applicable laws on controlled substances?
Breast milk management	In appropriate environments (eg, nurseries), does the system store data needed to administer breast milk (patient and mother identifiers, expiration dates)? At the time of delivery of the breast milk to the patient, does the system capture data that validate the correct matching of patient to milk aliquot?
Data norms	Does the system display the percentile value of each height, weight, and head circumference in every place where such data are displayed? Does the system indicate abnormal blood pressure based on age and height? Does the system store and display age-dependent normative ranges as supplied by the clinical laboratory? Does the system allow graphical plotting of laboratory values over time, with age-based normative ranges that change over the life span? In cases in which documentation by exception is used, are physical examination findings that normally change with age (eg, Babinski sign, unsteady gait) shown as normal at appropriate ages?
Privacy	Does the system store and display clear guidance to the user about who can access the record in cases of adoption of foster care? In the case of systems that allow parental access to the record (eg, a Web-based portal), can the system limit this access to match the level of assent of an adolescent? Does a way exist to represent multiple guardians or health care agent relationships in the system?
Terminology	In the portion of the EHR in which diagnoses are recorded, can the user specify rare congenital syndromes without resorting to free text? Can the problem list include items that are not typically considered specific diseases (eg, *high-risk social situations, developmental delay, immunizations up to date, vaccine refusal,* or *school avoidance*)? In recording birth history, can the system distinguish specific terms that apply to the mother from those that apply to the baby (eg, diabetes of the mother that affected the baby as a fetus)? Does the system allow retrieval of all patients with a particular diagnosis, symptom, or physical finding?
Granularity	Are ages displayed in units that are appropriate to the patient's age (eg, 3 weeks of age is not shown as 0 months of age)? Can the user enter weight to the nearest gram or other suitable precision?
Pediatric decision support	In the case in which guidelines are supported, can the system omit guidelines that are appropriate only for adults? Can the system filter reminders by age to reduce the number of inappropriate alerts? Can the system trigger reminders based on age combined with other data such as diagnosis or time since last encounter?
Adolescent privacy	Can the system's Web-based patient portal features match practice policy about who can access the adolescent's record? Are there ways to flag certain types of information as confidential? Can printouts or data displays accessible to parents be tailored to adolescents' privacy requests, within the boundaries of practice policy and applicable law?

BMI, body mass index; *CDC*, Centers for Disease Control and Prevention; *EHR*, electronic health record; *FDA*, US Food and Drug Administration.

NECESSARY FUNCTIONS OF AN ELECTRONIC HEALTH RECORD IN THE PEDIATRIC SETTING

Growth Monitoring

Fundamental to the practice of pediatrics is the analysis of growth, as documented by height, weight, and head circumference. In the United States, curves showing the distribution of these measurements at each age are published by the Centers for Disease Control and Prevention and the World Health Organization; special curves for premature infants and populations of children with specific congenital conditions such as achondroplasia, Down syndrome, Turner syndrome, or Williams syndrome are also available. Caution must be used in applying these special charts to a given patient because, in some cases, the data on which they are based were collected before the availability of treatments that may improve growth rates. Standard practice is to plot these values on the appropriate curve at each encounter. Although the use of growth charts in this way has not been expressly validated, it is a practically universal practice in pediatrics. Manually plotting these points is laborious and prone to error. Computer systems into which these data are entered can easily display a plot of growth data over time, just as they can produce a temporal plot of other clinical data. Pediatricians expect that these plots will behave in much the same way as paper plots; with careful attention to design, computer-based growth charts can retain the analytic usefulness of the paper curves while adding functions that no paper system can hope to offer. The evaluation of any EHR intended for use in the pediatric setting should include a careful examination of growth chart functions, including calculation of body mass index and body mass index percentiles by age and gender. (See Table 3-2 for specific questions to ask.)

Immunization Management

A common yet complex task in pediatric practice is determining which immunizations are due and when they are to be administered. The rules for indications and dosing intervals change at least every year and often more frequently as new vaccines come to market and as the epidemiologic factors of preventable diseases change. Many EHR systems sold today do not offer the pediatrician any decision support for this task, and a significant minority will not record immunizations. Immunization management is one of the more obvious functional areas in which a computer can improve the pediatrician's efficiency, yet the large difference in complexity between child and adult immunization management poses an often insurmountable implementation challenge to vendors of EHR systems. The ideal system will alert physicians regarding overdue immunizations whenever the patient's EHR is accessed, or at some future date when an encounter is planned (see Table 3-2 for appropriate questions to ask).

As EHRs are used more for population health (the management of groups of patients outside the context of individual patient encounters), these systems will become powerful tools for improvements in vaccine coverage. Population health tools in EHRs can facilitate outreach interventions that have been shown to improve immunization coverage.

Medication Prescribing

To a much greater degree than in adult care, pediatric prescribers compute doses of medications based on a recommended dosage of drug to be used per unit of body weight. Although body surface area and ideal body weight are sometimes used in pediatrics, actual body weight is the most common basis for dose calculations in general pediatric practice. Although most EHR systems offer prescribing, not all offer weight-based dosing support for many reasons, including lack of standardization of dosages; although the US Food and Drug Administration (FDA)-approved labeling of drugs includes weight-based dosages for products approved for use in children, many products used in children are not FDA approved, and many have recommended dosages in drug handbooks that differ from the approved product labeling. Another barrier to computerized weight-based dosing decision support is the practice of rounding to convenient doses (eg, whole milliliters are multiples of a 5-mL amount), which makes calculating doses even more complex. In addition to providing weight-based dosing support, the best systems will also alert pediatricians regarding allergies to medications and possible adverse drug-drug interactions.

Data Norms

When interpreting data from children—especially numerical data—age (and sometimes gestational age, body measurements, or stage of sexual maturity) must be taken into account. For example, blood pressure in adults is easy to interpret without referring to any of these factors; if it is above 120/80 mm Hg, then it is abnormal. In child health care, interpreting blood pressure requires either time-consuming references to tables or the assistance of an electronic information system that incorporates pediatric norms. Assistance with interpretation using gender-, height-, and age-based norms is technically easy but often not implemented in EHRs. Pediatricians who are evaluating any clinical information system should pay particular attention to how the system assists the user with normative data (see Table 3-2). Figure 3-1 illustrates one of the more complex examples of what it means to have a rich pediatric context—the display of blood pressure and the accompanying percentiles to allow decision making.

Population health tools in the EHR should be able to identify those in need of care coordination based on age-related abnormalities, like body mass index, bodyweight percentile, and stages of hypertension.

Terminology

To be useful in decision support, terms used to describe clinical data (eg, symptoms, signs, diagnoses, tests) need to be stored as a member of a defined terminology set, rather than as free text. Although free-text storage of clinical concepts provides maximum

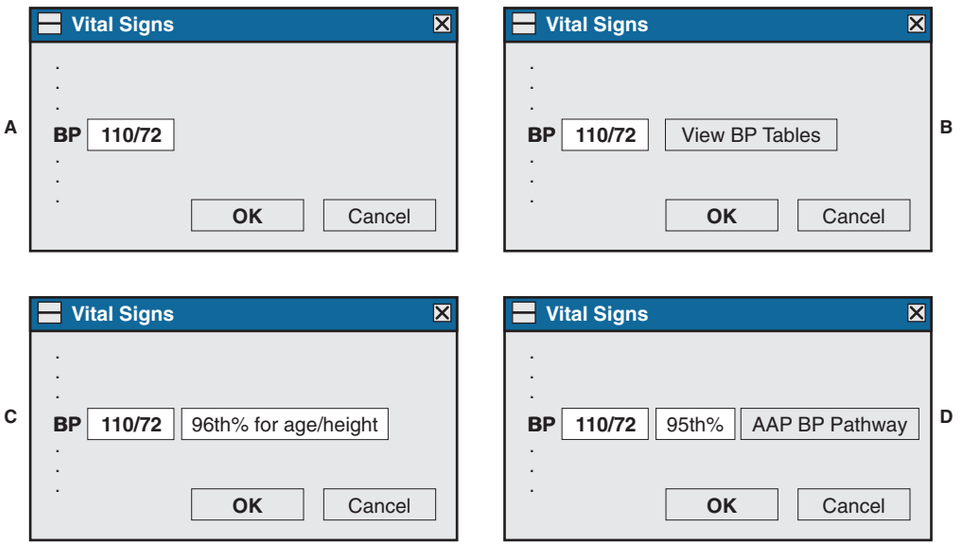

Figure 3-1 The pediatric context. The degree to which an electronic health record system understands cases in which pediatric care differs from adult care is a measure of its ability to present the pediatric context. Four fragments from a hypothetical user interface illustrate the different levels of pediatric context that a system can provide. **A**, Level 0: No recognition of pediatric factors. The system displays the patient's blood pressure. This behavior is expected, but it fails to reflect the pediatric complexities of blood pressure display. **B**, Level 1: Recognition of pediatric factors but no automation of special functions. The system begins to offer some pediatric context by offering the user the opportunity to look up norms for blood pressure in the same portion of the user interface that displays the blood pressure. **C**, Level 2: Recognition and basic automation. The system goes one step further by calculating the percentile value for the blood pressure (perhaps the higher of systolic or diastolic percentile values). **D**, Level 3: Recognition, automation, and integration with pediatric-specific evidence. The system calculates the percentile and offers to take the user to a pediatric-specific guideline pathway of some sort.

flexibility (and often speed) to the user at the point of care, free-text data entry is subject to typographic errors, redundancy, and the use of nonstandard terms. There are some emerging techniques that allow analysis of free-text clinical entries, but physicians cannot realize the full value of an EHR without some amount of encoded data.

The most readily available encoded data from clinical information systems has been claims data because these tend to be generated reliably. The biggest drawback of the use of claims data in pediatrics is that the terminology system used to encode diagnoses, the *International Classification of Diseases, ninth edition, Clinical Modification (ICD-9-CM)* is often not detailed enough to adequately express important diagnostic concepts. Although *International Classification of Diseases, tenth edition, Clinical Modification (ICD-10-CM),* mandated for implementation by the US Center for Medicare and Medicaid Services by October 1, 2015, offers slightly more granularity, the extra detail it includes has little clinical importance. There will always be a need for clinical terminology sets that are detailed enough to meet the requirements of physicians at the point of care. Terminology as displayed in the user interface should employ terms physicians use to describe concepts. SNOMED-CT (Systematized Nomenclature of Medicine—Clinical Terms) offers some promise in this area, but EHR vendors more commonly offer proprietary terminology systems like IMO (Intelligent Medical Objects, Northbrook, IL, e-imo.com) or Medcin (Medicomp Systems, Chantilly, VA, www.medicomp.com).

Granularity

Pediatrics involves smaller units of time, weight, and distance than adult health care. The scale of these measurements varies with age and with care setting. For example, age to the nearest minute is important in the delivery room, but in the newborn nursery, age to the nearest hour is usually sufficient (eg, for evaluating newborn screening laboratory results). In the first few months of life, the patient's age should be expressed initially in days, but later in weeks and then months. Body weight to the nearest gram is required in the neonatal intensive care unit setting, but is not usually necessary in the outpatient follow-up of older infants. Doses measured in fractions of a milliliter are necessary for some medications. EHRs intended for use with young infants should be able to adjust units of measure to the appropriate scale for the situation at hand. The evaluation of any EHR system should encompass its capacity to manage basic data on very small and very young infants.

Aliases

Name changes are more common in children than in adults because of naming conventions at birth. Names associated with laboratory values obtained for a newborn may not match the name of the patient when the infant is brought to the pediatrician's office for primary

care. Name changes may also occur for children as a result of divorce, remarriage, or adoption. EHRs should be able to store and allow searching for results based on multiple aliases.

Patient and Parent Education

Most EHR systems, and many stand-alone systems, offer electronic sources of information for parents and patients. For these sources to be effective in pediatrics, this educational information needs to be available in versions that are appropriate—in both wording and reading level—for variable parental reading levels. Many authorities recommend that these informational materials be written at a fourth-grade level. Materials for infants should refer to the patient in the third person, and material for adolescents should be written in the second person.

Data Source

Information in adult care comes from the patient in most cases. In pediatrics, a parent provides most information, but schools, other family members, and a potentially complex system of guardians and representatives may also contribute to data on a child. EHR systems should support an indication of the source of medical history.

Adolescent Privacy

An ideal for care held out by adolescent medicine specialists is that adolescents should be able to seek care without being forced to reveal certain information to their parent or guardian. This need for confidential care becomes accentuated when clinical information systems share information with guardians and when state laws dictate policy along these lines. To offer this ideal of confidential care, therefore, an EHR must accommodate an array of functions aimed at limiting dissemination of information, or at least being able to comply with practice policies and laws aimed at who is allowed to see adolescents' health information. Examples of these functions are listed in Table 3-2.

MANAGING CHILDREN WITH CHRONIC ILLNESSES AND POPULATION HEALTH MANAGEMENT

For a physician caring for children with chronic illness, the quantity and complexity of information make the EHR a necessity. By simply storing and organizing this clinical information, the EHR facilitates the maintenance of an effective medical home for children with chronic or complex disease. But the EHR can do more than just store the information; it can provide decision support to increase the likelihood that the right care is given at the right time. Although this decision support can take the form of automated alerts, there are simpler, less obtrusive forms as well, such as order sets, documentation templates that incorporate care guidelines, and care plans that may be specific to a particular diagnosis or risk.

A population health tool within the EHR that will be of increasing importance to those who care for children with chronic illness is the *registry*. A registry in an EHR is fundamentally a list of patients. Membership in this list can be determined automatically (through a diagnosis-based inclusion rule) or manually by clinical users. Registries in an EHR typically present selected data points for each patient that are relevant to the monitoring of disease state, such as viral load laboratory data for HIV patients or last hemoglobin concentration for children with sickle cell disease. Registries also typically support the display of severity scores, which, in turn, can be used to drive prioritization of outreach efforts.

Of course, population management tools such as registries can be used to target areas of health needs outside chronic care. A registry that identifies patients who are due for (or behind in) immunizations can boost immunization rates. The same can apply to well child care or other forms of health supervision. This kind of data-driven outreach is fundamental to the modern concept of the medical home.

As more physicians adopt EHRs, there are more opportunities to provide patients and families with direct access to their own records and to allow them to contribute data directly through personal health record portals. The ubiquity of smart phones and other Internet-connected devices makes it possible for families of children with chronic disease to view the medical record, complete surveys online, and even file data directly to the EHR. This data entry has the potential to get families more engaged in care while moving the data collection process closer to the patient. As EHRs make it more possible to perform care management activities outside the context of the office visit, direct interaction of the family and patient with the record will become more important. Patient portals should support appropriate features to protect adolescent privacy according to practice policy. For example, if it is the policy of the practice to restrict parents' online access without the adolescent's assent, the system should allow management of that assent.

DECIDING TO IMPLEMENT AN ELECTRONIC HEALTH RECORD

In a small practice, the decision to implement an EHR system, the choice of vendor, and the responsibility to fund it fall to the physician. In larger practices or in an academic medical center, these decisions take place in the hands of a committee, which must try to accommodate the needs of diverse physician groups with a solution from a single vendor. These decisions are complex, time-consuming, and momentous. Despite the widely touted assumption that the use of EHRs improves the quality of care, this claim has never been validated for an EHR system as a whole. Although individual pieces of an EHR have been shown to improve adherence to health supervision guidelines, documentation completeness, and incidence of medication errors, the sparse results on health outcomes have been mixed. The best reason to implement an EHR in pediatric practice is to automate and control processes that serve the larger goal of providing excellent care. The EHR should give pediatricians the opportunity to spend less time on mundane tasks, such as following documentation

guidelines, and more time on important tasks, such as talking to families and proactively managing their patient population within the medical home in a team environment.

Several methods can be used for approaching the first step, which is choosing a list of EHR systems to consider implementing.

- *Integration:* The most important predictor of success in an EHR implementation is how well the system works with existing information systems in the environment, especially systems that are critical to the financial success of the clinical operation. Most physician groups and hospitals begin their EHR project by looking at what systems work with their practice management and administrative systems.
- *Peer recommendations:* Another powerful influence over the product-selection process is word-of-mouth recommendations from professional peers. The American Academy of Pediatrics (AAP) Council on Clinical Information Technology supports these communications through its meetings, electronic mailing list, and Web site (aap.org/informatics/cocit.html). Although there have been efforts to create descriptions of what functions are needed in child health, there is no certification process that a physician can use to gain assurance that a given product works in pediatric settings. Demonstrated usefulness in setting similar to a physician's own setting is still the best way to know how well the EHR can work. Of course, variations in what version is implemented and decisions made as to how it should be implemented make each EHR installation different from the next.
- *Purchasing consortia:* Children's hospitals, physician practice organizations, medical societies, and health data exchange organizations often organize group purchasing arrangements or subsidies to allow practices to purchase EHRs and support services at a lower cost. Although these business arrangements do not necessarily ensure greater usability of the software, larger consortia of purchasers carry more clout in driving the decisions about how the product is designed and implemented. Furthermore, such consortia often have experience installing systems in similar practices, have learned what works in the community, and can provide an instant group of experienced peers to help a practice through the transition.

After candidate systems have been selected, most physicians attempt to evaluate them systematically by interviewing vendors and attending demonstrations. Professional meetings, including those sponsored by the AAP, offer an efficient way of beginning this process through exhibit halls or public competitions between systems. Site visits to practices that are similar to the physician's own are expensive, but offer the most realistic information on how the system performs. The value of site visits is limited by the fact that no 2 practices are alike and that current users may offer a biased opinion about a system purchased and implemented at great cost.

The cost of EHR systems is the most frequent barrier cited by physicians to EHR implementation. No easy answer exists to the question of how much an EHR costs. Pricing plans vary greatly from vendor to vendor, and no vendor offers a pricing plan that a physician can apply without a lengthy interaction with a sales representative. Old published data from the American Academy of Family Physicians suggest that an EHR system costs approximately $5,500 per physician per year, with the cost rising to $7,200 per physician per year for a combined EHR and practice management system that includes billing, patient scheduling, accounts receivable, and similar nonclinical functions. Open-source EHR software, in which the software itself is included in the price, may not be any cheaper than commercially sold software, given that the bulk of an EHR system's cost comprises installation, setup, and ongoing support. EHR software vendors are creating pricing plans at all points along the spectrum, hoping to capitalize on tradeoffs that physicians are willing to make to keep the price low.

A recognized factor in the success of any EHR system implementation is support among the physicians who will be using the system. Implementing an EHR system is disruptive to a practice because it changes almost all established work patterns. EHR implementation also requires physicians and staff to agree on the best procedures for a given task because computerization tends to require uniform procedures. An essential component is to have a *physician champion* who has major responsibility for the EHR implementation in the practice. This person should be a genuine leader in the practice. In addition to the physician leader (and, perhaps, leaders in other job roles), the practice needs to decide on a process for introducing the system into its work. The 2 general implementation approaches are the *big bang,* in which a given system is brought up to full operation over a very short period (eg, a week), or the gentler, but slower, incremental approach, whereby pieces of the system are put into place gradually and used more and more over a longer period. Another technique for introducing an EHR system in a manageable fashion is to either reduce the number of patients to be seen during the rollout (not an economic possibility for most pediatricians) or to use the system on only a small number of patients per day at first. The incremental approach with graduated numbers of patients is feasible but extends the period in which the practice must operate in an environment in which some information is on paper and some is in the EHR.

The full transition to an EHR system, in which no paper charts are used at all, is another challenge to EHR implementation. Information in the paper chart is useful and necessary for a long time (years, in some cases). Manually entering data from the old charts should be done only for the most complex patients, whose charts might benefit from manual sifting of old data. For most patients, scanning of selected pieces of paper (growth charts, immunization records, latest clinic visit, latest consultant reports) may be sufficient. Alternatively, the physician can simply continue to pull paper charts for the visits and enter new data in the EHR as needed. This task can continue until enough time has passed that the paper charts are no longer worth having for most patients. As long as a data source is of sufficient quality (ie, has reliable

patient identifiers), some data may be worth loading into the new EHR electronically. For example, even basic data like encounter dates or claims data can give useful context for patterns of care. Most pediatricians will continue to maintain physical storage facilities for old paper charts because of statutory requirements, but the cost of maintaining this storage will eventually shrink because of the declining need to access archival data.

The question of whether the cost of an EHR system has a financial return is legitimate. Although savings can be demonstrated from electronic order entry because of avoidance of errors in hospitalized adults or from reductions in redundant imaging because of access to exchanged data, research on the return-on-investment question is not extensive for a wide variety of practice scenarios. Some of the benefits of an EHR system accrue to people and organizations other than the physician. For example, if physicians are asked to provide immunization data from their EHR to update the state immunization registry, in all likelihood the entire cost of this project will fall to the practice.

For the pediatrician's practice, EHRs can significantly reduce personnel costs by eliminating the pulling, filing, and locating (often extremely time-consuming) of paper charts for office visits, telephone calls, and prescription refills, among other duties. EHRs can also dramatically reduce the labor required to gather data for quality reporting purposes, provided the system is set up to capture the appropriate data elements. Other cost savings from EHRs are listed in Box 3-1.

Whether time is saved documenting care depends on the state of the user's paper-based documentation in the first place. If the most common Medicare and Medicaid guidelines are followed when coding for evaluation and management services, then the EHR will undoubtedly perform this task faster and more accurately than any paper system. Often in pediatric practices, the paper chart system does not comply with these guidelines. Implementation of an EHR can raise the bar dramatically for documentation detail, given that Medicare compliance is a major selling point for these systems in adult care. Because the trend suggests that documentation compliance guidelines from all payers will be getting stricter, a system by which an EHR is the only way a physician can be expected to generate the detail necessary to justify payment may be a foregone conclusion, regardless of efficiency considerations.

BOX 3-1 Cost Savings of Electronic Health Records to Practice

- Reduction or elimination of transcription costs
- Elimination of missing charges
- Reduction of medical records staff time and storage space
- Elimination of time spent waiting for chart pulls or finding paper charts
- Reduction of rework attributable to illegible or off-formulary prescriptions
- More efficient tracking of laboratory results and referrals
- Reduction of resources spent managing phone calls (if secure messaging is used)

DIAGNOSTIC DECISION SUPPORT

The use of a computer to aid in the diagnosis of children with challenging presentations has been a tantalizing possibility since the dawn of the computer age. Diagnostic decision support systems (ie, systems that can take a list of signs and symptoms and suggest possible diagnoses) with pediatric clinical domains have been available for years, yet few physicians use these systems, and demand for such systems has been so low that few vendors of commercial EHR systems have attempted to integrate an automated diagnostic decision support program into their products. It is more common instead to offer links to medical texts from the EHR. Perhaps when EHRs become more widespread, resurgence in interest in the use of these diagnostic aids will take place, if they can be integrated into new patterns of work. More practical means of decision support exist commonly in EHRs, like order sets that suggest standard treatments or documentation templates that remind the physician about ideal care.

AAP POLICY

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SUGGESTED READINGS

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Chapter 4

EVIDENCE-BASED MEDICINE

Brett W. Robbins, MD

Evidence-based medicine (EBM) is the conscientious, explicit, and judicious use of current best evidence to solve clinical problems. It requires integration of individual clinical expertise and patient preferences with the best available external clinical evidence from systematic research and consideration of available resources. EBM provides the pediatrician with an explicit process to locate, appraise, and apply clinical research reports to patient care. The 4-part process of EBM (ask, acquire, appraise, apply) provides an organized framework to facilitate bringing evidence to the point of patient care.

WHY BOTHER?

The proliferation of medical literature is rapid. A large number of new randomized trials are published each month. To keep abreast of advances in health care requires an organized approach that includes methods to verify the validity of the information. Another reason for using an organized approach to examine the medical literature is that clinical practice is rich with questions. On average, for every 3 outpatients seen, physicians have 2 questions that are pivotal to the care of these patients. A similar number of questions arise during the care of inpatients. EBM is therefore worth the effort because it allows physicians to remain current with best practices and improve patient outcomes.

Step 1: Ask

Formulating an answerable and searchable clinical question is the the first step of the EBM process. It focuses the busy physician on exactly what is needed to provide patient care. Spending a few minutes to formulate and format a good clinical question is well worth the investment because this effort saves time later in the searching process.

The 2 types of questions in clinical medicine are background and foreground. Background questions deal with disease-specific information and the basics of a condition. An example of a background question is, "What is ondansetron and how does it work?" The answers to background questions are most often found in standard textbooks and review articles. Foreground questions deal with patient-specific information regarding the diagnosis, prognosis, or therapy of a condition. Unlike background questions, the answers to these questions are best found in the medical literature. Time is saved searching for answers to foreground questions if they are first expressed in the format known as PICOTT: **p**atient, **i**ntervention, **c**omparison, **o**utcome, **t**ype of question, and **t**ype of study format. An example of a foreground question is, "In children with acute viral gastroenteritis, does ondansetron reduce symptoms and prevent admission?" Putting this question into the PICOTT format focuses busy physicians on exactly the answer they are interested in finding and begins the search process (Box 4-1).

Step 2: Acquire

Physicians acquire information from the medical literature in 2 ways: passively (gathering) and actively (hunting). Physicians gather information when they peruse articles that come to them, either through subscription or happenstance. Acquiring the article takes little effort, but the author of the article, not the physician, defines the question. This process is further limited by a lack of context for the article because other data that may exist on this same question are not

BOX 4-1 Example of a Foreground Question

Patient: Child with acute viral gastroenteritis
Intervention: ondansetron
Comparison: Placebo
Outcome(s): Reduction of symptoms, prevention of admission
Type of question: Therapy
Type of study needed: Randomized controlled trial

Table 4-1 Schema for Ranking Sources of Evidence

SOURCE	SUMMATIVE	VALID	PREAPPRAISED	SYSTEMATICALLY SEARCHED
Cochrane Database of Systematic Reviews (www.cochrane.org)	+	+	+	+
Evidence-Based Clinical Practice Guidelines (www.guidelines.gov)	+	+	+	+
Clinical Evidence (www.clinicalevidence.com)	+	+	+	+
Essential Evidence Plus (www.essentialevidenceplus.com)	+	+	+	+
ACP Journal Club (www.acpjc.org)	–	+	+	+
InfoPOEMs/InfoRetriever (www.infopoems.com)	–	+	+	+
Textbooks/Up-to-Date (www.uptodate.com)	+	–	–	–
AAP Grand Rounds (aapgrandrounds.aappublications.org/)	–	–	–	+/–
PubMed (www.pubmedcentral.nih.gov/)	–	–	–	–

+ = yes, – = no; +/– = somewhat.

known. Thus, although gathering requires little energy, it also leaves little under the direct control of the physician.

Hunting is actively pursuing an answer to a physician-generated PICOTT question. In general, the search terms are drawn directly from the PICOTT question itself. Time is best spent hunting in grounds known to have valid, preappraised, and summative evidence (Table 5-1). The best databases will have done most of the work already. Physicians should search in a database where they know that all the information has been systematically searched to include everything that exists on the topic. The gold-standard database in this regard is the *Cochrane Database of Systematic Reviews*, which is a database that is systematically searched, preappraised, and up to date. The reviews are updated about every 2 to 3 years. *Evidence-Based Clinical Practice Guidelines* and *Clinical Evidence* are also systematically searched and preappraised. These sources are also updated periodically. A clearinghouse database of all high-level databases is *Essential Evidence Plus* (www.esssential evidenceplus.com), where busy physicians can search all of the high-tier and rigorously searched databases at one site. Second-tier databases include summaries of individual articles such as the *ACP Journal Club* and *InfoPOEMs,* both of which contain some pediatric literature. If these sources are unrevealing, the physician can search in databases that are unfiltered for validity such as PubMed (see Table 4-1 for links to these databases). Early in a physician's career is the best time to form a strong working relationship with the medical librarian, who can assist with questions and assist in accessing these databases.

Step 3: Appraise

Once an article is located, the next step is to determine its validity. The *Users' Guides to the Medical Literature,* published by JAMA, is an excellent resource. The relevant types of study designs are described using principles of epidemiology, from randomized controlled trials to cost-effectiveness analyses. A clinical example is used to lead the reader through 3 tasks: assessing validity, quantifying results, and applying the evidence to patients. Table 4-2 is an example of some of the common study types and the information that is found in the User's Guide. It also includes the most efficient method of finding each type of article in PubMed.

Assessing Validity

Each study type in the *Users' Guide to the Medical Literature* has a list of criteria to determine if a study is valid. These criteria are based on epidemiologic principles and are explained in detail using a clinical example. The criteria appear roughly in their order of importance, but they are not intended to lead to a dichotomous decision of being valid or not valid for a study. Rather, they are intended to assist the physician in determining the relative validity of the study and thus the relative strength of its results. If a study is not valid, then its results are in question and should not be used in the clinical decision-making process. An example of the validity criteria for therapy (randomized-controlled trial) is found in Box 4-2.

Quantifying Results

The *Users' Guide to the Medical Literature* provides methods to determine the magnitude of effect of an intervention in a more clinically meaningful way than is offered by *P* values. Each type of article has its own methods and terms, such as number needed to treat (NNT) for therapy, likelihood ratios (LR) for diagnosis, and relative risk (RR) for prognosis. For example, the NNT is calculated by dividing 100 by the absolute difference between the outcome rates of the intervention and placebo groups. The result is the number of patients that need to be treated to prevent one bad outcome or to cause a good outcome. For example, in a study of 215 children presenting to the emergency department with mild to moderate dehydration from viral gastroenteritis, of those randomized to treatment with ondansetron, 14% vomited in the next 1-hour oral rehydration period after medication administration. Of the patients randomized to placebo, 35% vomited in this hour. This result was statistically significant ($P < 0.001$), with an NNT of 100/(35–14) or

Table 4-2 Commonly Confused Terminology in Evidence-Based Medicine

STUDY TYPE	TIMELINE	LOGISTICS	STATISTICS USED	COMMENTS	HOW TO FIND ON OVID MEDLINE
Randomized controlled trial (therapy or prevention)	Prospective	Single group of patients randomized to 2 or more therapeutic or screening methods	Relative risk reduction; absolute risk reduction; number needed to treat	Gold standard; most powerful information	Limit to randomized control trial publication type
Cohort (prognosis)	Prospective or retrospective	Single group of patients gathered at a common point in their diseases and followed forward in time	Relative risk—*predicts* outcomes	A comparison cohort may or may not exist Framingham study is good example of retrospective cohort	Combine the following MeSH heading with subject search—expand cohort studies
Case control (harm)	Retrospective	Group of patients with the disease compared with group of patients without the disease Look backward for exposure(s)	Odds ratios—*predicts* exposure(s)	The most difficult to control for bias when conducting	Combine the following MeSH heading with subject search—expand case-control studies
Diagnostic test (diagnosis)	Prospective (optimally)	Single group of patients at risk for a disease; All get tested	Sensitivity Specificity Likelihood ratios Odds ratio	This point is where physicians use pretest and posttest probabilities along with thresholds	Combine the following MeSH heading with subject search—expand "sensitivity and specificity"
Meta-analysis (overview)	Retrospective look at multiple studies	All relevant studies addressing the same question combined mathematically as if they were one large trial	Effect size	Can combine any of the study types, most commonly therapy and diagnosis	Limit to meta-analysis publication type

BOX 4-2 Validity Criteria for a Randomized Controlled Trial

Did experimental and control groups begin the study with a similar prognosis?
- Were patients randomized?
- Was randomization concealed?
- Were patients analyzed in the groups to which they were randomized? That is, did an intention to treat exist?
- Were patients in the treatment and control groups similar with respect to known prognostic factors? That is, were baseline characteristics equal?

Did experimental and control groups retain a similar prognosis after the study started?
- Were patients aware of group allocation?
- Were physicians aware of group allocation?
- Were outcome assessors aware of group allocation?

Was follow-up complete?

about 5. Thus the physician would need to treat 5 children with mild to moderate dehydration with ondansetron rather than placebo to prevent 1 from vomiting in the next hour. In addition, at the end of the hour-long oral rehydration period 14% of the ondansetron-treated children and 33% of those receiving placebo needed intravenous (IV) rehydration. (NNT ~ 6), but hospital admission rates were no different (4% vs 5%). Other outcomes that are nondichotomous, such as length and volume of IV fluid needed and time in the emergency department, were in favor of ondansetron as well. An NNT cannot be calculated from this type of continuous data unless an arbitrary cutoff is set to make the outcome dichotomous (eg, the percentage of children who spent more than 4 hours in the emergency department). The NNT is more clinically meaningful than a simple *P* value and helps the physician balance risk and benefit more explicitly. Not only is a low NNT important, it is also necessary to understand the risks and benefits of the treatment and underlying disorder to

make an informed decision regarding the proposed therapy. In this example, children in the ondansetron group on average had 1.4 episodes of diarrhea in the oral rehydration hour vs 0.5 episodes on average for the placebo group ($P < 0.001$). Again, an NNT cannot be calculated from this continuous outcome. The only other adverse event would be cost of the medication, but one needs to look at overall costs of IV hydration as well when comparing costs.

The NNT is difficult to interpret without its precision, or 95% confidence interval. For our ondansetron example, given that the study population is of moderate size ($N = 215$), the confidence intervals around our NNT of 6 for intravenous rehydration are moderately wide (3-17). Thus we are 95% certain that our true NNT falls somewhere between 3 and 17.

Step 4: Apply

After determining that an article is valid and quantifying its results, the final step is to decide whether it applies to the patient. This process has less to do with the inclusion and exclusion criteria than with the patient's underlying physiologic condition. Inclusion and exclusion criteria are written for logistic purposes of the study itself rather than for the person to whom the information can be applied. Patients who may not have met inclusion criteria for the study may still benefit from the study results. However, if something in the patient's underlying physiologic condition is very different from the patients in the study, then the findings from the study may not apply to this particular patient. In the case of the ondansetron study, the physician might be appropriately hesitant to apply this evidence to children presenting for vomiting from other etiologies such as increased intracranial pressure.

In making the decision whether to use valid evidence for a particular patient, the physician must balance 4 factors: the evidence, her or his own clinical judgment, the patient's values and preferences, and the clinical state and circumstances at the time the decision needs to be made (Figure 4-1). The physician must decide how much weight to give each of these 4 factors in making the decision. The process of EBM provides the validity and thus strength of the evidence. In doing so, it does not replace clinical judgment, but rather informs it. Patients have the right to refuse an effective intervention with valid evidence behind it, even if the intervention is judged to be worthwhile. Furthermore, even if an intervention is proven to be effective by valid evidence and the physician and patient agree to use it, the intervention may not be readily available or financially viable. This fluidity of interaction of these 4 issues results in different decisions on different days with the same evidence, and perhaps even with the same patient.

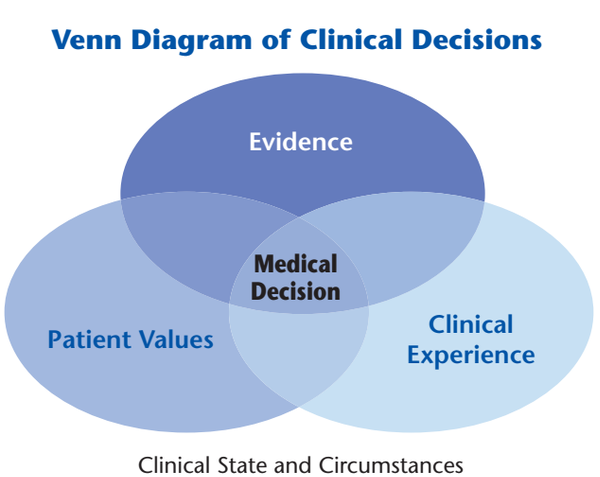

Figure 4-1 Venn diagram of clinical decisions.

TIME

For EBM to be useful to the busy pediatrician, it has to be time efficient. Three suggestions might make EBM efficient in a busy practice. First, the more physicians use the process, the more efficient they become. Learning the EBM process mimics learning how to perform a history and a physical examination; efficiency comes with time and practice. Second, hunt and gather in databases that are known to be fertile. Focus on databases such as *Essential Evidence Plus*, the *Cochrane Database, Clinical Evidence*, and *www.guideline.gov* In doing so, clincians can be assured that the information obtained has been thoroughly searched, assessed, and summarized. Third, hunt and gather only those questions that are common to actual practice, are critical to an individual patient's care, or involve subjects about which physicians are intensely curious.

GETTING STARTED

The *Users' Guides to the Medical Literature* is the best resource on how to learn, practice, and teach EBM because it is complete, easy to read, and well organized; it also comes with a CD-ROM and on-line version with all the mathematics distilled to simple calculators. When an article from the literature is read, the *correlate chapter* feature should be used to guide the assessment of the article. Over one-half of the foreground questions asked in practice deal with therapy, diagnosis, and disease management. Thus, if physicians are adept at critically appraising these types of articles, then they are well prepared to answer most of their clinical questions. The next time a clinical question is worth the time to research, the physician should start with one of the fertile databases. If the inquiry is a common question or about a common disorder, then in all likelihood relevant evidence that is preappraised, presearched, and presummarized will exist.

CONCLUSION

Patients deserve to have physicians who make decisions regarding their care based on sound evidence. EBM provides an explicit, transparent process to track down information, assess its validity, and apply it to individual patients. It does not replace sound, seasoned clinical judgment, but rather informs it. A growing

array of resources is now available that makes the process timely and thus useful to the busy primary care pediatrician.

TOOLS FOR PRACTICE

Medical Decision Support

- *BMJ Clinical Evidence* (book), British Medical Journal (www.clinicalevidence.com/ceweb/index.jsp)
- *Essential Evidence Plus* (Web site), (www.essentialevidenceplus.com)

AAP POLICY

American Academy of Pediatrics Steering Committee on Quality Improvement and Management. Classifying recommendations for clinical practice guidelines. *Pediatrics*. 2004;114(3):874–877 (pediatrics.aappublications.org/content/114/3/874)

SUGGESTED READING

Guyatt GH, Rennie D. *Users' Guides to the Medical Literature. A Manual for Evidence-Based Clinical Practice*. Chicago, IL: JAMA Press; 2001

Chapter 5

QUALITY IMPROVEMENT IN PRACTICE

Charles J. Homer, MD, MPH; Victoria W. Rogers, MD

INTRODUCTION

Quality of care has become a central theme in the delivery and management of health care. The focus on quality results from consistent data indicating that health care in the United States has a "serious and pervasive . . . overall quality problem," and that "the burden of harm conveyed by the collective impact of all of our health care quality problems is staggering."

Data from both inpatient and outpatient settings in pediatrics show widespread gaps in care. A recent, detailed analysis of ambulatory health care for children found that children receive recommended care less than one-half of the time, and the performance of children's health care was 10 percentage points lower than a comparable assessment of adult care.

Fortunately, methods and tools that enhance the quality of care are increasingly available and can be applied in primary care settings. Programs to enhance care have been successful in improving preventive services and the care of children with both acute and chronic conditions. This chapter reviews these methods and provides practical guidance for applying them in practice.

DEFINITIONS

The Institute of Medicine (IOM) defined *quality* as "the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge." This definition, which provides a foundation for current thinking, acknowledges the importance of outcomes, the key roles of individuals and the public in determining which outcomes matter, the essential role of probability (doing the right thing even if the right result does not always occur), and the constraint placed on current quality of care by the current state of knowledge.

The IOM refined its definition in the report, *Crossing the Quality Chasm,* which outlined 6 specific aims for the health care system, now widely viewed as the critical dimensions of quality. These aims, provided here along with explanations behind them, are that health care be

- *Safe:* Safety (defined here as protection from harm as a consequence of health care) is a system property rather than a reflection of individual shortcomings; system redesign is the necessary strategy to address shortcomings in this area.
- *Effective:* Effective care refers to the reliable delivery of care that is known to be more likely to achieve desired results; that is, care that is consistent with evidence when available with appropriate consideration of individual patient characteristics and preferences.
- *Efficient:* Efficient care refers to the judicious and appropriate use of resources or, more specifically, not delivering care known to be ineffective (eliminating overuse).
- *Patient centered:* Patient centeredness is the core, central aim of health services. The fundamental definition of quality refers to outcomes desired by patients as the key aim of care. The experience of care is one dimension of patient centeredness, and satisfaction with care is one component—a subjective assessment of how these experiences compare with expectations. In child health, this is better framed as patient and family centeredness.
- *Timely:* Timeliness refers to eliminating the delays that are omnipresent in health care; it is a dimension that clearly affects efficiency and patient centeredness, and it affects safety (eg, delay in providing a needed immunization as a result of scheduling) and effectiveness (delays in appointments for appropriate medical tests and therapies).
- *Equitable:* Quality applies to the care of all patients, not simply subsets of patients in the care of the physician. The IOM report *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care* demonstrates that disparities of care exist throughout the health care system and calls for widespread educational and improvement efforts to eliminate them.

Until recently, quality improvement efforts in primary care focused on 1 or, at most, 2 aspects of quality—such as effectiveness (eg, use of appropriate medications for asthma or rates of immunization) or patient centeredness (typically measured in terms of patient satisfaction). Nonetheless, the IOM concept of quality suggests that high-quality programs that meet the needs of children and families are characterized by excellence in all 6 areas. Practices that provide the best care deliver the right care—based on evidence and

associated with the best outcomes—in a manner that is respectful of family needs and values, that wastes neither resources nor time, that does not cause preventable harm, and that is delivered without bias and designed to achieve equitable results across different patient populations. Timeliness of access is an attribute of the practice's delivery system; geographic and financial access are attributes of the larger health care finance and policy system rather than attributes of the practice system itself.

Because of the nature of primary care, care must be designed to address the full spectrum of child health needs—preventive care, acute care, and the care of children with chronic or special health care needs. In most cases, care should also address community needs, including both societal health needs (eg, high immunization rates) and the particular public health concerns of the community served by a practice. This latter emphasis is consistent with the pursuit of the "Triple Aim"—simultaneously improving health, improving the experience of care (framed as the 6 IOM dimensions discussed previously) and reducing per capita costs. The Triple Aim is the most recent reframing of quality, initially developed by the Institute for Healthcare Improvement and now incorporated into the US Federal National Quality Strategy. From this perspective, practices need to help address the broader social needs of their patients, and must also be aware of the impact of earlier life experiences on long-term health and well-being.

The fundamental requirement for addressing all of these issues in a practice is to view the primary care practice as a system or, in some cases, as one component of a larger system such as a medical group, hospital network, or accountable care organization. When viewed as a system, the methods and tools of improving system performance can be applied to practices.

Establishing Priorities

Given the breadth and scope of quality, as well as the substantial gaps in performance across the spectrum of quality dimensions, choosing where to begin is daunting. One strategy to inform the choice of priorities is the use of a monitoring tool such as a quality compass, balanced scorecard, or family of measures. Although such dashboards or scorecards are often viewed only in the context of corporate management, the concept here is to develop a set of indicators that reflect practice performance across the 6 dimensions of quality for a practice, as well as across other dimensions that practices already likely monitor, such as financial performance and staff satisfaction. Such a management tool can assist practice leadership in setting priorities. Often, external organizations, such as managed care plans, require measures in 1 or more of the quality dimensions, and national quality award programs, such as the Baldridge Award, look for such a systematic approach to priority setting and performance monitoring.

In choosing to develop and apply a monitoring tool, practices should first consider their overall purpose in establishing a measurement system. Although these tools can be used to comply with insurance requirements and identify priorities for mandated projects, a more appropriate purpose is to enable practices to provide appropriate, timely care for the child and the child's family, with the overall goal being to promote better health outcomes for children, families, and the community. Because practices need to stay organizationally vital to provide this care, a reasonable additional aim is to sustain the organization over the long term.

What should a monitoring tool measure? Individual practices or practice networks may choose different measures, but an ongoing commitment to quality includes monitoring across the full spectrum of care.

In the area of safety, practices can measure several dimensions. One critical aspect of safety in primary care is reporting and responding to critical test results. This can be assessed by identifying abnormal values from laboratory results and tracking the proportion of patients with these results who were notified appropriately or had appropriate follow-up actions documented.

The measure of timeliness in primary care is increasingly standardized. The most widely used measure is the time to the third available appointment in a practice (regardless of visit type). Another measure of timeliness that assesses the performance of the broader health system is the wait for a subspecialty appointment (using the same third-available construct).

Measuring the effectiveness of care should include all 3 aspects of care—acute, chronic, and preventive.

Acute care is a major component of pediatric primary care. Fewer firm measures of care exist in this field. Among the most widely used measures of the quality of acute care is the appropriate use of antibiotics, a measure now widely in use through the Healthcare Effectiveness Data and Information Set (HEDIS), a standard set of measures used to assess quality of managed care plans developed by the National Committee for Quality Assurance. This measure tracks the rate of antibiotic prescriptions for children between 3 months and 18 years of age who were diagnosed with upper respiratory tract infections.

Numerous metrics are available to assess the effectiveness of care for children with chronic conditions. The most widely used metrics relate to care for children with asthma, the most common chronic medical condition. These metrics include measures of care processes, such as whether severity is assessed or whether appropriate medications are prescribed, and measures of patient outcomes, such as hospitalization, emergency department visits, and days without symptoms over a specified period. Measures also exist for the care of children with attention-deficit/hyperactivity disorder (ADHD) that are broadly consistent with the guidelines of the American Academy of Pediatrics (AAP). These measures include the use of criteria established in the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (*DSM-5*) in making the diagnosis and undertaking appropriate follow-up after the prescription of a stimulant or other medication. Measures of symptoms and function can also be collected to provide a more comprehensive assessment of care quality. More rigorous measures of effectiveness combine, or bundle, multiple measures into a single *raise-the-bar* indicator, requiring that all

appropriate processes be undertaken for a specific patient (eg, assessing severity, using a written management plan, and prescribing appropriate medication for a child with asthma).

Because the needs and concerns of families with children with special health care needs are quite similar regardless of the specific condition, broad measures assessing the degree to which practices fulfill these needs are available. These measures assess, among other items, how well practices coordinate care and link families to available resources. Such measures can be obtained from the "Children With Chronic Conditions" item set of the Consumer Assessment of Healthcare Providers and Systems (CAHPS) survey. These measures rely on the most appropriate source of information—the parent or caretaker.

Preventive care is the most commonly assessed aspect of primary care for children. Typical measures of effectiveness of preventive services include immunization rates, the performance of screening tests (eg, developmental assessments), and the provision of anticipatory guidance consistent with recommendations. The recent dramatic increase in childhood obesity has led to specific emphasis on the quality of preventive care related to this condition. These measures typically include performing the body mass index percentile calculation, categorizing the obesity risk status, and providing counseling about appropriate health behaviors.

A more sophisticated approach to assessing the quality of preventive services might entail assessing whether a patient-specific health risk assessment was undertaken and whether appropriate follow-up assessments and plans were developed depending on these risks. Parent-reported measures of preventive care—particularly related to promoting appropriate development—are also available (see Tools for Practice).

Measures of efficiency in primary care pediatrics are often monitored by practices themselves or by third-party payers; these measures might include provider productivity, use of high-cost pharmaceuticals or radiologic tests, and hospitalization or emergency department use.

Patient and family centeredness can only truly be assessed by patients and families themselves. The dimensions of these measures are typically included in patient experience-of-care surveys and usually consist of

- Perceived access
- Courtesy and respect
- Provision of information
- Involvement in decision making
- Care coordination
- The physical environment of the practice
- Overall assessment

These dimensions have been assessed on a widely available plan-level measure, the CAHPS. A medical group and practice-level CAHPS for child health has recently become available.

The measurement of equity of care is relatively simple in concept, but has often been controversial in implementation. To assess equity, practices need a reliable indicator of membership in a particular group (eg, racial group, income or insurance category, language spoken). Then, all the other measures in the scorecard can be stratified by the different categories (examining, for example, whether rates of prescribing appropriate medication for patients with persistent asthma vary by race or whether critical test follow-up rates differ according to language).

If practices identify improving community health as one of their aims, then tracking broader community-based measures of health will also be appropriate, such as rates of injury caused by intentional or unintentional trauma and population-based indicators of obesity and diabetes. These data might lead to specific practice-based initiatives or might prompt more active engagement in advocacy and program development within the broader community. Such data are often available through local and state health departments or may be found online at the state, county, or city level. See, for example, County Health Rankings & Roadmaps (www.countyhealthrankings.org/rankings/data).

A comprehensive practice measurement set combines these clinical metrics with additional performance metrics, such as financial performance and measures of staff satisfaction. Practice leaders developing such scorecards for a single practice within a larger system must also realize that maximizing performance on a single unit is typically not the goal of an overall institution, so care must be taken to avoid policies that negatively affect performance elsewhere. For example, maximizing productivity in a practice by referring all complex patients to specialists may decrease access to those specialists for other practices.

Primary care practices do not typically undertake comprehensive monitoring and assessment. The burden on an individual practice of compiling these measures regularly in the absence of an effective clinical information system, such as an electronic health record and effective practice registries, is substantial. On the other hand, the ability to generate such performance data and then use the data to manage and improve quality within a system is a clear advantage of electronic health information systems and one of many arguments for the potential benefit of such systems. Making such measures transparent (ie, sharing them publicly with staff, patients, and the community) may also serve to deepen widespread engagement and generate ideas for improvement.

Measurement does not result in improvement in quality; rather, it is necessary to identify opportunities for improvement and for tracking progress towards a goal. For quality to improve, measurement must be linked to purpose, better ideas for how to practice, and a process that reliably produces change and enhanced results.

UNDERTAKING AN IMPROVEMENT PROJECT

Regardless of the priority chosen, the fundamental approaches used in improving quality at the practice level are similar. The first step is chartering a team to undertake improvement. In a small practice, the team might consist of the entire practice—physician, nurse, and manager. In a larger practice, improvement teams typically include part of the practice, but must maintain ongoing communication with the rest of practice

so that improvements can subsequently spread. If the practice has a senior partner or some other form of formal leadership, then the leadership should develop the charge for the team. The team should be multidisciplinary and, in almost all cases, should involve patients and families as team members.

Establishing Aims

The first task of an improvement team is establishing an aim, which may need to be refined by leadership (See Figure 5-1). Aims for improvement programs should be based on data and should be sufficiently bold to engage the energies of the project team. Similar to any research hypothesis, aims should be directional and specify magnitude. Aims should be closely aligned with the mission and vision of the organization and, whenever possible, reflect the priorities of patients and families. A hypothetical aim statement might be, "Our project aim is to increase the function of children with ADHD cared for in our practice; we will do so by improving the care of children with ADHD so that more than 95% receive perfect care, without disparities"; in this case, *perfect care* is precisely defined (eg, use of *DSM-5* criteria for diagnosis, development of shared goals, use of evidence-based treatment, and follow-up consistent with AAP guidelines). This example clearly indicates the interrelatedness of the 6 quality aims. Although ostensibly focused on effectiveness of care (giving evidence-based treatment for ADHD), the project will also necessarily involve issues of safety (monitoring for side effects and complications), efficiency (use of mental health specialists), timeliness (wait times for assessment and treatment), patient and family engagement, and, given the current lower level of use of evidence-based treatments among black children who meet criteria for this diagnosis, equity.

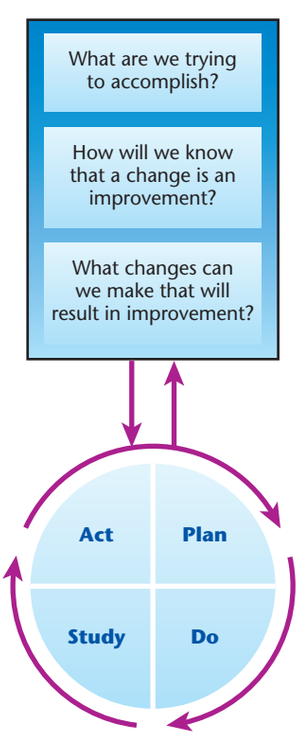
What are we trying to accomplish?
How will we know that a change is an improvement?
What changes can we make that will result in improvement?
Act
Plan
Study
Do

Figure 5-1 Model for Improvement. *(From Langley GL, Moen R, Nolan KM, Nolan TW, Norman CL, Provost LP.* The Improvement Guide: A Practical Approach to Enhancing Organizational Performance. *2nd ed. San Francisco, CA: Jossey-Bass Publishers; 2009. Reprinted with permission.)*

Selecting Performance Measures

The second step in an improvement program is establishing measures to assess performance and track gains. Measuring for improvement generally should focus only on the most important elements of the work. Ideally, measures should be derived from data collected routinely in the course of care, such as through an electronic health record or patient registry or through ongoing patient survey activity, but in most cases this must be supplemented by project-specific data collection and analysis. Importantly, data should be plotted and tracked over time using simple tools, such as run charts, or more sophisticated tools, such as control charts, rather than aggregated for evaluation-oriented before-and-after studies. A typical improvement project will include between 4 and 8 measures, including measures of the processes of care (was the right thing done?), of the outcomes of care (did the right result occur?), and of potential adverse outcomes (balancing measures; did unintended harm occur?). In the example, ADHD measures of process would include whether information about child symptoms and function was collected from a parent and 1 other source (eg, a teacher) and whether *DSM-5* criteria were used. Outcome measures might include symptom scales and measures of function. Balancing measures might include patient satisfaction and physician productivity.

Identifying Good Ideas

The third step for an improvement initiative is identifying changes or innovations that are likely to lead to accomplishing the desired aims. Ideas for such changes can often be found in the medical literature, with recognition that medical innovations often take between 1 and 2 decades to enter widespread use after being proved effective. Changes can also be found outside of health care; safety innovations, for example, are typically imported from high-reliability industries such as aviation, nuclear power, and high-speed transport. Patients, families, and health care staff are additional valuable sources of innovation. Generic change concepts from industry are another useful source of innovation that can be customized to the health care setting.

Example of a Good Idea: Care Model for Child Health in a Medical Home

An idea that is widely applicable to improving the quality of primary care—particularly preventive care and the care of children with special health care needs—is the care model for child health in a medical home, a modest modification of the chronic care model

developed by Wagner and colleagues (Figure 5-2). The care model asserts that primary care is best delivered not by an individual provider, but rather by a health care team, and that the team will best serve the patient if it can anticipate patient needs and act accordingly. The team can function most effectively when supportive clinical information, decision support, care delivery, and self-management support systems are in place within a practice or clinic and when larger organizational systems are also aligned in support of the overall approach. The care model further asserts that patients must participate in their own care as members of the care team. To accomplish this task, patients need sufficient knowledge, skills, and abilities to monitor and manage their well-being. For younger children, a parent or caregiver often serves as the patient's voice and agent. The care model advises that health care practices and systems draw on community resources to help patients achieve better outcomes.

Practices with appropriate clinical information systems are able to list which of their patients have specific clinical conditions (eg, asthma), the severity or complexity of these conditions (eg, severe persistent asthma), and other bits of information relevant to the patient management question at hand (eg, are all eligible children with asthma using the proper dose of anti-inflammatory medication?). Information systems can also indicate which patients have received specific preventive services (eg, immunization, screenings, and assessment of healthy weight) and provide reminders when they are due.

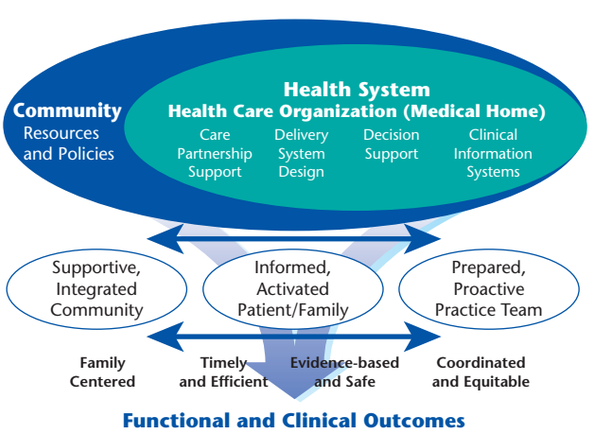

Figure 5-2 The care model for child health in a medical home. This diagram indicates the desired outcomes of excellent care for children; the shared contribution of the health care system and community resources to improved results; the key role of organizational policies and leadership; and the four specific elements of an effective medical home—information system, decision support, delivery system design, and care partnership support. *(From Homer CJ, Cooley WC. Creating a medical home for children with special health care needs. In: Sobo EJ, Kurtin PS, eds.* Optimizing Care for Young Children with Special Health Care Needs. *Baltimore, MD: Paul H. Brookes; 2007, with permission.)*

Two aspects of the design of the delivery system merit particular attention. Interactions among physicians, other health care providers, patients, and families should be designed to address issues of importance to patients and their families and to anticipate future needs. The most effective settings for such interactions are planned visits. Planned visits are routine in preventive care (well-child visits) but are less common—although essential—in the care of children with special health care needs. Because of the fragmentation of services for children, the care model for child health also emphasizes care coordination. A designated office staff member may provide care coordination, or care coordination functions may be distributed in clearly defined ways among several individuals. Finally, because children are ethnically and culturally diverse, capturing ethnic information in patient registries is important to ensure that practices can examine their care and outcomes by patient subgroups. Trained interpreters in the care partnership enable appropriate goal setting and care planning.

Chronic care must be based on evidence when evidence is available and on expert guidance when evidence is not available or needs interpretation. Basing care on evidence requires mechanisms for determining what type and degree of evidence is required to drive change, for obtaining and reviewing evidence-based recommendations, for sharing such information with patients and families, for entering the evidence in medical record systems so that faulty memory does not impede care, and for maintaining ready access to subspecialty expertise.

The most critical component of the care model is providing care in a way that promotes patients' ability to provide self-care and manage their own care. This framing acknowledges that pediatricians and other health care professionals are facilitators and that the actions of patients are the final determinants of outcomes. The core aspect of self-management support is the development of shared goals between patients and physicians and the subsequent development of specific, mutually agreed-on plans to achieve these goals.

Because care for children includes supporting both the family's ability to provide care and the child's ability to assume self-care, practices should provide both self-management support (supporting the ability of the child to manage their own health and health care) and family-management support (that is, promoting the ability of the family to manage that care). For example, children with diabetes or asthma need to take increasing responsibility for monitoring their own condition and for adjusting their medical regimen as they approach adolescence. The medical home, where the care model is implemented, needs to support the child's increasing competence in managing her well-being and to counsel and support the family in monitoring the success of that effort while also maintaining the child's safety.

The care model highlights 2 additional areas critical to providing preventive care and care that meets the needs of persons with chronic conditions. The first area is alignment of health care provider activities with organizational aims. The second is that practices must draw on the resources of the larger community

to meet patient needs. This includes obtaining access to not only formal supports and entitlements such as housing services or special education, but also informal supports provided by resources such as churches and libraries.

Although not simple, the care model for child health is a powerful framework for the organization (and reorganization) of pediatric primary care. Combined with evidence-based guidelines as well as an effective strategy to undertake small changes that will ultimately effect large changes in practice systems, it results in better care for children and families. This model provides the detail that is needed to make the medical home concept a reality.

Implementing Change

In primary care practices, fully implementing a new approach, such as the care model described previously, in a way that anticipates all the challenges that such change will bring is not typically possible. A more effective approach to introducing change is through the use of repeated small tests of change, sometimes referred to as the Shewhart cycle after the industrial engineer who first developed the approach, or more commonly, the plan-do-study-act (PDSA) cycle.

The PDSA cycle starts with the question, "What is the largest meaningful test of change that we can conduct by next Tuesday?" The priority for a PDSA cycle is to expeditiously try something out (do) in a way that is planned and that allows learning (study) and revision (act). A typical health care PDSA cycle involves the care of one patient at one point in time by one health care provider, such as the use of a new dehydration assessment form or patient instruction diagram. A full cycle involves planning what will be done (including the questions of who, what, where, and when, if not why), performing the test, reflecting on what happened during the test, and modifying the test for the next cycle. Effective improvement programs conduct numerous cycles, building one on the other and addressing different dimensions of the care system with different series of tests.

This approach to improvement—the combination of aims, measures, changes, and the PDSA cycle—is known as the Model for Improvement. Developed by Associates in Process Improvement, the Model for Improvement is among the most widespread improvement frameworks in health care. Different approaches use different terminology and have somewhat different emphases but in general they share the use of aims, measures, and repeated tests of change.

COLLABORATIVE LEARNING

Sharing data allows individual organizations both to set priorities better and to identify practice settings that have better performance for learning (also known as *benchmarking*). The benefits of collaborative learning have formed the basis for numerous collaborative improvement programs in children's health care. Many networks initially established for clinical and health services research, including the AAP Pediatric Research in Office Settings and the Continuity Research Network for academic primary care, have the potential to serve this purpose. Topic-specific learning collaboratives conducted by the National Institute for Children's Health Quality and other organizations can also serve this function. Many regional improvement programs have also been established, often involving state professional association chapters working together with public health officials, academic institutions, and public and private health insurance agencies. Participation in such external efforts typically accelerates learning and improvement and facilitates the pediatricians' efforts in quality improvement, which are often difficult to accomplish without external resources.

SUMMARY

Widespread deficiencies abound in health care across all 6 dimensions of quality (safety, timeliness, effectiveness, efficiency, equity, and patient centeredness). A systematic approach to monitoring quality can help set priorities for improvement, although the specific topics and initiatives to be undertaken must also be customized to the specific institutional environment. Use of a quality improvement approach such as the Model for Improvement increases the likelihood of making positive changes in care and outcomes. The care model for child health is one powerful idea that can be used to organize and improve the quality of primary care practices, particularly when combined with evidence-based recommendations such as Bright Futures. Collaboration across organizations can accelerate improvement efforts as well.

TOOLS FOR PRACTICE

Community Advocacy and Coordination

- *Be Our Voice: Obesity Prevention Advocacy Training* (online course), National Institute for Children's Health Quality (obesity.nichq.org/resources/obesity%20prevention%20advocacy%20training)
- *Bright Futures, Theme 10: Promoting Community Resources and Relationships* (guidelines), American Academy of Pediatrics (brightfutures.aap.org/Bright%20Futures%20Documents/11-Promoting_Community_Relationships.pdf)
- *Community Toolbox* (Web site), Work Group for Community Health and Development, University of Kansas (ctb.ku.edu/en)
- *Tools and Resources* (Web page), National Center for Medical Home Implementation (medicalhomeinfo.aap.org/tools-resources/Pages/default.aspx)

Practice Management and Care Coordination

- *Care Coordination Task Force Key Elements Framework (report)*, Massachusetts Child Health Quality Coalition (www.masschildhealthquality.org/wp-content/uploads/2014/06/care-coordination-framework.pdf)
- *Child Clinician and Group CAHPS Survey* (Web page), Agency for Healthcare Research and Quality (cahps.ahrq.gov/Surveys-Guidance/CG/index.html)
- *Creating a Patient and Family Advisory Council: A Toolkit for Pediatric Practices (booklet)*, National Institute for Children's Health Quality (medicalhome.nichq.org/resources/pfac-toolkit)
- *For Practices: Getting Started* (Web page), National Center for Medical Home Implementation (medical

homeinfo.aap.org/tools-resources/Pages/For-Practices.aspx)
- *Medical Home Change Package*, National Institute for Children's Health Quality (medicalhome.nichq.org/resources/medical%20home%20change%20package)
- *Putting Theory Into Practice: A Practical Guide to Medical Home Transformation Resources* (Web page), Patient-Centered Primary Care Collaborative (www.pcpcc.org/guide/putting-theory-practice)

AAP POLICY

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American Academy of Pediatrics Steering Committee on Quality Improvement and Management. Toward transparent clinical policies. *Pediatrics*. 2008;121(3):643–646. Reaffirmed February 2014 (pediatrics.aappublications.org/content/121/3/643)

SUGGESTED READINGS

AAP Professional Resources on Practice Support: Quality Improvement (www.aap.org/en-us/professional-resources/practice-support/quality-improvement/Pages/Quality-Improvement.aspx)

Center for Medical Home Improvement (www.medicalhomeimprovement.org)

National Institute for Children's Healthcare Quality (www.nichq.org)

The Institute for Healthcare Improvement (www.ihi.org)

Chapter 6

MEDICAL HOME COLLABORATIVE CARE

Jeanne W. McAllister, BSN, MS, MHA; W. Carl Cooley, MD

BACKGROUND

The complexity of health maintenance, acute illness care, and chronic condition management no longer permits the simple model of a single practitioner meeting all of the health care needs of every child in every family. The primary care family-centered medical home requires an organized team of providers and staff working together to ensure the safest, most effective, and most efficient delivery of care. At least 15% of children have 1 or more special health care needs, and their care often requires the involvement of specialists as well as other health and non-health community resources. Well children may also require referral to specialists for troubling signs or symptoms of disease or when screening in the medical home raises suspicion of a problem. Health maintenance for all children suggests a broad population approach. Depending on the risk patterns of children in a practice's population, this approach may require communication with and linkage to public health resources. All of these interactions involve collaboration both within and beyond the walls of the medical home.

FIVE LEVELS OF COLLABORATION

The primary care family-centered medical home occupies a crucial intersection within the community-based system of supports and services on which families, children, and youth depend (Figure 6-1). The medical home is positioned to collaborate and coordinate care vertically within the health care system as well as horizontally among community-based organizations. As a result, much depends on a proactive approach to collaborative care. To realize a fully integrated, family-centered, community-based system of care and services, collaborative care must manifest itself in 5 domains. First, and central to the provision of family-centered care (see Chapter 9, Partnering With Families in Hospital and Community Settings), pediatricians and other providers of pediatric care promote a true partnership with families. This is the relationship around which all other collaborations revolve. Second, the staff of the primary care medical home functions as a team with explicit roles for all members aimed at providing the most effective, efficient care and the best possible experience for families. Third, the primary care medical home team collaborates with specialists around initial consultations and ongoing chronic condition care to ensure seamless comanagement and clarity about diagnostic impressions and treatment plans. Fourth, the medical home team needs to work with insurers (private and public) and accountable care organizations to ensure appropriate

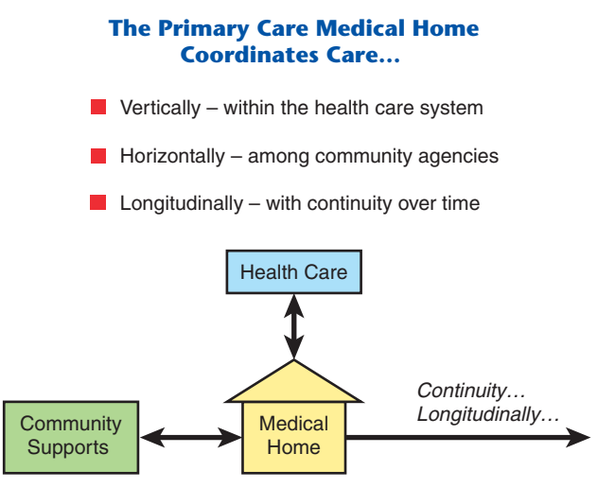

Figure 6-1 Medical home responsibilities.

access to and payment for their patients' care. Finally, the primary care medical home collaborates with other community-based organizations such as schools, early intervention programs, mental health agencies, home health agencies, and family support organizations to ensure that a child's health care needs are fully understood and considered in the context of the whole range of community services that impact the child and family.

Family-Centered Care: Collaboration With Patients and Families

Family-centered care was defined by an expert panel of health care professionals, family leaders, and maternal and child health policy makers in the following manner:

> Family-Centered Care assures the health and well being of children and their families through a respectful family-professional partnership. It honors the strengths, cultures, traditions and expertise that everyone brings to this relationship. Family-Centered Care is the standard of practice, which results in high quality services.

A growing evidence base demonstrates improved outcomes for children and families receiving family-centered care. In particular, studies have demonstrated lower hospitalization rates, reduced rates of unmet needs, and increased use of community services. Furthermore, family-centered care has been associated with improved physical and mental health and fewer missed school days for children with chronic conditions. Families receiving family-centered care are more satisfied with care to which they have easier access and about which they have better communication.

Family-centered care has evolved over the past 30 years to become integral to all pediatric health care whether in the hospital, the outpatient department, the emergency department, or the primary care medical home. It is grounded in the understanding that the family, however it may be configured, is the constant in the child's life and crucial to health, development, and general well-being. In the provision of all aspects of primary care (preventive, acute, and chronic), the medical home team must regard the family as a full partner in the health care of each child with a shared stake in both decision making and outcomes. Chapter 9, Partnering With Families in Hospital and Community Settings, addresses family-centered care in more depth.

Team-Based Care: Collaboration Within the Medical Home

In the late 20th century, the pediatric primary care office consisted of individual physician providers of care supported by a variety of staff members, depending on the size of the practice. The staff might have included a receptionist at the front desk, a nurse or medical assistant to escort patients to examination rooms and assist the physician with procedures, and someone to handle billing and financial matters. Larger practices might have more physicians, an office manager, a medical records manager, and additional front desk staff and nurses. However, to a large extent, everyone's role was to support individual office encounters between patients and their families and the primary care physician. Surveys of families described high levels of satisfaction with their primary care physicians. However, as the health care system and the health care needs of children and youth have become more complex, the traditional model of care proved to be less efficient, effective, and accessible, and even less safe than it needed to be.

In the past 20 years, new members of the typical pediatric office staff have materialized, including nonphysician providers such as advanced practice registered nurses (nurse practitioners), child health associates, and physician assistants and medical assistants to handle patient flow in the office. Some primary care practices have added the role of a care coordinator who may work with families, particularly those with children with special health care needs, to ensure timely planning, access, and follow-through with needed services. More importantly, the delivery of care in a primary care medical home has required that office staff members collaborate in more defined ways as care delivery teams. The growth of team-based care has paralleled the adoption and spread of the medical home model as a means of ensuring comprehensive, coordinated, easily accessible care. In the medical home, the pediatrician leads a team that is concerned not only about caring for individual patients, but also about promoting the overall health of the population it serves. The members of such a team have specific roles to play that are clearly articulated and understood by everyone and that ensure that each team member functions at the top of their training, expertise, and licensure. The expectation for expanded access to the primary care medical home with evening, weekend, and holiday office hours, as well as interactive Web sites and patient portals, requires that teams can cross-cover for one another and still retain knowledge of a panel of patients. As more of the pediatric workforce serves in part-time positions, team-based care in the medical home provides necessary continuity while also providing enhanced access to care. Such expanded access with continuity of care has demonstrated cost savings in emergency department utilization and admissions.

A large pediatric primary care medical home may include several teams delivering care to a specific panel of patients. This team might include a lead pediatrician, 2 or 3 nonphysician providers, several medical assistants, and a care coordinator. This primary care team would meet each morning in a brief "huddle" to examine the list of patients scheduled for the day, determine if there are any special or unanticipated needs, and identify who may need help with care coordination or, among patients of the nonphysician providers, who will require physician consultation. Such meetings have been shown to improve patient flow, reduce waiting times, and reduce the risk of overlooking a problem. In the course of a busy day, the care coordinator will make contact with specialty clinics, hospitals, schools, and community agencies on behalf of patients with special or complex needs, freeing the direct care providers (physician and nonphysician) to see patients with fewer interruptions.

The medical home team not only needs to perform as a collaborative team, but also shares a responsibility for the quality and cost of the care it delivers. In a medical home, teams may create and receive reports about the clinical outcomes they are achieving, about the satisfaction of the patients and families they serve, and about costs of care incurred by those patients and families. Armed with such data, the medical home team also functions as a quality improvement team as it reflects upon its performance and then discusses, tests, and evaluates ways to improve the care that is delivered. Wherever possible, this process of continuous improvement solicits the input and suggestions of patients and families as consumers of medical home services. Further discussion of quality improvement in the medical home can be found in Chapter 7, Planned Coordinated Care to Support the Medical Home.

Comanagement of Chronic Conditions: Collaboration With Specialists

Pediatric specialists provide critical, often lifesaving evaluation and care for children and youth with chronic conditions and can be an important source of decision-making support for primary care pediatricians and other professionals. Patients with suspicious symptoms or screening results are referred to specialists for diagnostic confirmation, and those found to have chronic conditions may require ongoing management from specialists. The presence of a chronic health condition requiring specialty care poses the risk of care being fragmented into the chronic condition management provided by specialists and the routine preventive and minor acute illness management provided by the primary care pediatrician. With the advent of the medical home model, the role of the primary care team in the management and coordination of care of chronic conditions has become better defined and valued. An ample body of evidence supports better outcomes for children with chronic conditions who receive care in a medical home. Clear communication between the primary care pediatrician and specialist is essential to ensure that they both understand what roles they will be playing in caring for the patient.

On the other hand, beyond a few conditions like asthma and attention-deficit/hyperactivity disorder (ADHD), many chronic conditions affecting children are uncommon, and a growing number of children have combinations of conditions that complicate their care. Specialists in the diagnosis and management of these conditions may believe that only they are equipped with the knowledge, experience, and technological resources needed to produce the best results. Some specialists may regard primary care physicians as too uncomfortable, too ill-informed, or even too disinterested to participate in the management of rare or complex conditions. However, the primary care medical home is the only entity in the health care system that is positioned to both communicate and coordinate within the system (eg, with specialists) and with community-based organizations that may be important for a child with a complex, chronic condition. The key is a process of explicit, coordinated comanagement in which the role of the specialist and that of the primary care medical home team are clearly defined and reliably communicated in a bidirectional manner. Such planned comanagement ensures that the specialist makes critical care decisions while the primary care medical home has clear information about the treatment plan, a role in monitoring the patient's status, and the ability to triage new symptoms or problems. Some chronic conditions may stabilize enough to allow for an expanded primary care role in management with a reduction in specialty care involvement over time, and other conditions may fluctuate between periods of routine management and periods of high specialty-care needs.

Effective collaboration between the primary care medical home and specialists involves planning and communication. The electronic medical record—particularly with electronically interoperable interfaces with specialists, imaging, and laboratories—helps facilitate the necessary explicit, bidirectional communication for comanagement of children with chronic or complex conditions. The collaborative care roles of subspecialists and primary care pediatricians must be planned, explicitly defined, and understood by all involved. That planning manifests itself in a written care plan. Ideally, the care plan becomes the instrument of communication as it is shared among the specialists, the primary care medical home, and the patient or family. These 3 could be regarded as the core collaborative care team, because each of them must understand and accept his or her role in the comanagement process. To do so, each must work from the same proposed care plan. This is often best addressed by using a patient portal that is available to primiary care pediatricians, subspecialists, and patients' families alike.

In some situations, particularly within large integrated systems of care, the relationship between certain specialists or specialty groups and primary care pediatricians for relatively common conditions and/or situations may have clearly articulated parameters and expectations that apply to all shared patients and clinical situations. Such comanagement or service agreements spell out the expected actions of the primary care team alongside the expected availability and actions of specialists. For example, for children with seizures, the neurologists may agree to see new patients for evaluation in a timely manner and communicate their findings and plans rapidly, and the primary care team may agree to provide some of the seizure follow-up, obtain anticonvulsant blood levels, and share the findings with the neurologist. By sharing some of the follow-up management with the primary care team, the neurologist will have better access for new patients on her schedule.

In some situations, the specialists may have a team that is very capable of providing comprehensive care to patients with chronic illnesses, thereby functioning as a medical home for those patients. This can be an appropriate alternative model to the primary care medical home as long as there is clear communication about the roles of the specialist teams and the primary care medical home so that there is no confusion regarding who provides the various aspects of care.

Community Outreach: Collaboration With Community-Based Organizations

Children and their families are high utilizers of community-based services. Child care, preschool services, early intervention programs for infants and toddlers, public and private schools, and community mental health services provide supports to children and families. In many instances, particularly in settings like child care and school where children spend many hours each day, important health issues arise frequently and collaboration is important. Children with chronic conditions like asthma, diabetes, and ADHD may require the administration of medication at school, and school health officials will need up-to-date information about overall management. Children affected by rare conditions may manifest symptoms at school that need accurate assessment, and children with some complex health care needs may receive enteral feedings or require respiratory care while at school. Early intervention programs conduct ongoing assessments of developmental progress in children with developmental delays that should be integrated with medical information in those children's health records. The work culture in a busy primary care office practice is different than that of an elementary school, often making direct communication difficult. However, a care coordinator serving as a member of the primary care medical home team may communicate regularly with counterparts in various community-based organizations, creating a better flow of information and establishing a more personal relationship between the medical home and the community agencies.

Because the medical home can be regarded as providing an interface between personal, individual health and public health in the community, the medical home team will also need to collaborate with public health agencies and officials. From the reporting of communicable diseases to immunization registries to the follow-up of newborn screening tests, the effective and timely exchange of information can be critical. State Title V programs are responsible for ensuring access to appropriate care and treatment for all children with special health care needs and often have information and personnel to assist the primary care medical home in serving this population. An active, collaborative relationship with Title V agencies can help connect patients and families with resources that they need.

COLLABORATIVE CARE AND THE CULTURE OF THE MEDICAL HOME

The medical home model has helped operationalize new primary care functions or improve existing ones such as family-centered care, care coordination, access, and population-based care. However, the medical home transformation of primary care has also brought new cultural values that underlie all of the structures and processes of care. Chief among those new values is the commitment to quality and to continuous improvement, but a collaborative approach to care ranks as another important value. Intrinsic to collaboration is a respect for others involved in the common endeavor of good health, including the patient, the family, colleagues in the medical home, specialists, and local community service professionals.

TOOLS FOR PRACTICE

Engaging Patient and Family

- *Building Your Care Notebook* (Web page), American Academy of Pediatrics (medicalhomeinfo.aap.org/tools-resources/Pages/For-Families.aspx)
- *Emergency Information Form for Children with Special Needs* (template), American Academy of Pediatrics (www.aap.org/advocacy/blankform.pdf)
- *Hospital Stay Tracking Forms* (file archive), National Center for Medical Home Implementation (medicalhomeinfo.aap.org/tools-resources/Documents/Hospital%20Stay%20Tracking%20Forms.zip)
- *Medical Summary Part I* (handout), American Academy of Pediatrics (medicalhomes.aap.org/Documents/PediatricCarePlan.pdf)
- *Pediatric Specialists* (Web page), American Academy of Pediatrics (www.healthychildren.org/English/family-life/health-management/pediatric-specialists/Pages/default.aspx)
- *Positioning the Family and Patient at the Center: A Guide to Family and Patient Partnerships in the Medical Home* (monograph), National Center for Medical Home Implementation (medicalhomeinfo.aap.org/tools-resources/Documents/Positioning_FINAL_May24.pdf)

Practice Management and Care Coordination

- *APEX Digital Navigator* (practice transformation tool), American Academy of Pediatrics (www.aap.org/en-us/professional-resources/practice-support/APEX/Pages/Digital-Navigator.aspx)
- *Family-Centered Care Self-Assessment Tool* (self-assessment), Family Voices (www.familyvoices.org/admin/work_family_centered/files/fcca_FamilyTool.pdf)
- *Measuring Medical Homes: Tools to Evaluate the Pediatric Patient- and Family-Centered Medical Home* (monograph), National Center for Medical Home Implementation (medicalhomeinfo.aap.org/tools-resources/Documents/Monograph_FINAL_Sept2010.pdf)

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Chapter 7

PLANNED COORDINATED CARE TO SUPPORT THE MEDICAL HOME

Jeanne W. McAllister, BSN, MS, MHA; W. Carl Cooley, MD

BACKGROUND

A family-centered pediatric medical home provides proactive, planned, coordinated care. This is very much like the patient-centered medical home, but with a greater emphasis on the whole family. Primary care practices that achieve this standard are able to make 4 key claims: first, they can demonstrate how they enter into partnerships with families and work together to help families meet the needs of their children; second, the practice has chosen a model of family-centered, team-based care coordination; third, this model is expressly shared with families and delivered through a partnership that is jointly and continuously evaluated for improvement; and finally, the physicians and their teams find this partnership professionally gratifying.

Chapter 9, Partnering With Families in Hospital and Community Settings and Chapter 10, Family-centered Care of Hospitalized Children address collaboration across the continuum of health and community care. The purpose of this chapter is to define and describe care coordination in the medical home—its characteristics, processes, tools, and core functions. Care coordination is needed because fragmentation continues to plague our health care delivery systems. The medical home, family partnerships, and coordinated care are true counterparts; one cannot exist without the others. Highly functioning health care teams provide reliable and flexible options for full access to the medical home. Care in this environment uses proactive, planned, coordinated approaches, and does so with the help of family-centered, team-based care.

TEAM-BASED CARE COORDINATION

Bodenheimer defines a team as "a group with a specific task or tasks, the accomplishment of which requires the interdependent and collaborative efforts of its members." Effective teamwork is also described in terms of relational coordination, which requires shared goals, shared knowledge, problem solving, and frequent and timely communication, salted with mutual respect—blending the management of people and of their care tasks.

THE COORDINATION OF CARE

A key care process in the medical home is the provision of care coordination; often all or most team members provide some coordination functions. Care coordination is defined as a patient- and family-centered, assessment-driven, continuous, team-based activity designed to meet the bio-psychosocial needs of children and youth while enhancing personal and family caregiving skills and capabilities. Care coordination in the medical home provides for communication linkages with people within other health and community agencies. To be effective, care coordination functions should be centralized and implemented in a partnership with the patient and his or her family. A key result of team-based care coordination is a family supported in their own primary caregiving and coordinating role, and children and youth who are appropriately prepared to gain responsibility and confidence caring for themselves. Reliable, explicit, and systematic processes are needed to ensure timely, optimal, and consensual exchange of relevant information.

INTEGRATION OF CARE

Practice-based care coordination also emphasizes communication with nonmedical professionals at schools and within community agencies in order to advocate for children and families and establish shared care or service goals. There is a strong need for care continuity and for the integration of primary care efforts with other services and supports that children and families use. This is particularly true when circumstances include pediatric conditions requiring the input of multiple specialized physicians and therapists. The pediatric primary care medical home is ideally suited to centralize care and integrate the input of other physicians and professionals across the care and community continua (eg, home/school, clinic, hospital). Coordinating care and facilitating communication in this way is often referred to as "the warm handshake" of the medical home. Box 7-1 provides an example.

Care coordination in a highly functioning pediatric medical home meets the following criteria:

1. Patient and family centered
2. Community based
3. Proactive with planned, comprehensive care
4. Promotes the development of self-management skills among children, youth, and their families
5. Facilitates cross-organizational linkages, relationships, and multidirectional communication (including medical specialists and consultants and nonmedical providers such as schools and community agencies).

BOX 7-1 Case Example

Whitney is a 15-year-old who on her best days dreams of getting her driver's license. She has longstanding uncontrolled type 1 diabetes. Compounding social factors contribute to her school absences and even to truancy charges. In the 6 months prior to her switch to a new medical home with care coordination, Whitney had 9 emergency room visits and 7 hospitalizations resulting from ketoacidosis.

CARE COORDINATION OVERALL AIMS

- Effective management of type 1 diabetes
- Improved communication, collaboration, and coordination among teen, family, physicians, and school team

SHARED PLAN OF CARE GOALS

- Transition to insulin pump (pending her diabetes control)
- Obtain driver's license
- Improve school performance

SHARED PLAN OF CARE—NEGOTIATED ACTIONS (PERIOD OF 10 MONTHS)

- Enroll in a quality medical home
- Engage with care coordinator
- Support teen and family
- Hold/attend care conferences
- Update and detail the goal-related strategies within the shared plan of care
- Align partners
- Develop an emergency plan
- Increase contact, communication, and collaboration with medical home and school
- Overcome (persistent) communication and transportation barriers to counseling
- Work with diabetes educator 2 times per month
- Work with dietitian 2 times per month

RESULTS

- Access to a high-quality medical home with care coordination
- Use of the strategies and approaches within the shared plan of care
- Multiple collaborative contacts with medical home "neighborhood" or collaborating partners
- Counseling in place

UTILIZATION

Ten months after onset of care coordination with a plan of care, Whitney had 2 emergency department visits, no hospitalizations, improved A1C test results, and improved school attendance. Her insulin pump is pending.

WHO NEEDS CARE COORDINATION?

A variety of patient and family needs and circumstances warrant strong care coordination. Examples include a child who has recently been diagnosed with a chronic condition, a family navigating the multiple agencies involved in the care of their child, a child who requires multiple interventions or hospitalizations that may interfere with his or her school attendance or daily activities, and a child in foster or kinship care. Each child and family benefits from linkages to needed services and resources. Children and families with temporary or longstanding psychosocial concerns may also need help with the coordination of relevant care and services. Care coordination may be a short, time-limited process or part of a long-term continuous care relationship, or somewhere in between. An outcome of care coordination is an increasingly empowered family that knows where to look for assistance when needed. This means a primary care medical home must offer a clear message about all available care coordination supports.

The medical home team (with senior leadership, if appropriate), should decide whether care coordination will be available for every patient in the practice or delivered in some defined manner based on need. The team may target a specific patient population for available care coordination services. For example, they may decide that services will be directed towards a population of children/youth with special health care needs (CYSHCN). Such children have, or are at increased risk for, chronic physical, developmental, behavioral, or emotional conditions that require health and related services of a type or an amount beyond that required by children generally. The team may determine levels of care coordination service based upon care complexity. Care complexity will vary with changes in a child's condition and over time. The Child and Adolescent Health Measurement Initiative offers a screening tool readily available to every medical home at no cost to help with the identification of the population of CYSHCN in each practice. Care coordination has been shown to meet child and family needs and to have a positive effect upon health and cost outcomes.

Care coordination is meant by design to foster a strong relationship between families and the medical home and to link families to needed services and resources. Beginning with an identified population, the team can either reach out to targeted families or identify patients and families prospectively at the time of an office visit. These patients are typically enrolled in a registry (spreadsheet, database, or electronic tool) that stores health information in a way that supports proactive, planned, and coordinated care. A registry should include critical items for tracking and monitoring patients along with items necessary to help demonstrate best available known pediatric practice (eg, annual flu vaccine reminders) for purposes of program evaluation. Once a population is identified and enrolled in a registry it may be useful to stratify this grouping by applying a complexity score or sorting by level of concern. (To learn more, go to www.medicalhomeinfo.org to access the Building Your Medical Home Toolkit.) Organizing patients by levels helps the team to prioritize patient and family needs and apply limited care coordination resources in the most efficient and effective manner.

PROVISION OF CARE COORDINATION: STRUCTURES AND PROCESSES

When asked what they need to help them care for their children, families often request a team approach to care along with help coordinating efforts across

multiple services and settings. Families need to know that they have professional partners who will back them and a team that facilitates cross-organizational communication and collaboration. Care tools, such as portable care plans, help to pull these multiple pieces together into a coherent description of goals, assets, and needs with action steps to address them. Trusting relationships are therefore cultivated between and among children, families, and the medical home team.

Historically, the family experience of care has been one of fragmentation—the opposite of coordination. When care is disjointed, families encounter a confusing matrix of people, services, and systems instead of the synergy of supports that they need. Effective care coordination integrates these people, services, and systems, thereby increasing the value of care. Care coordination demonstrates this integration through timely, clear communication with patients and families, team members in the medical home, other health care providers across other settings, and community-based organizations.

A set of care coordination services should be defined and made available to families; such services or functions are outlined in the report *Making Care Coordiation a Critical Component of the Pediatric Health System: A Multidisciplinary Framework,* published by the Commonwealth Fund. Families need to know that these care coordination supports are available and how to access them. Awareness of practice-based care coordination can be achieved with descriptive brochures, posters, flyers, and information on the practice's Web site.

A CARE COORDINATION MODEL

Essential, continuous cycles of coordination include the use of assessments, care planning with mutual goal setting, care plan implementation, and monitoring with evaluation. (See Figure 7-1.)

1. **Assessment:** Identification of child and family needs is the first step in the care coordination process. Accordingly, medical home team members collect and review medical, educational, and other information and concerns. They also obtain information about family strengths, goals, needs, and available resources. This assessment might be broad or narrow, depending upon the family circumstances, and it should be repeated at predetermined intervals. Many primary care practices use a social worker, nurse, or family advocate to support these activities. (See Figure 7-2.)
2. **Care Planning/Goal Setting:** Child, youth, and family assessment results inform the creation of a comprehensive shared plan of care. Family and medical home team goals should guide this plan. While every child benefits from a plan of care, comprehensive care planning is critical for children with more complex needs or circumstances. Comprehensive care planning involves using intake information and assessment results to create a medical summary, an emergency plan (if needed), and an action plan. The medical summary includes relevant history, diagnostic concerns, medications and treatments, allergies, information about subspecialists and other key physicians involved, and any information the family wants each professional to understand about their child. The emergency plan supplements this with clear actions to take in response to an adverse event. Engaged patients and families, together with the physician and team, set goals for the management of care, self-care, and resource utilization. An action plan is developed with specific goals, objectives, and interventions to address specific concerns. The action plan component of comprehensive care planning clearly identifies who will be responsible for each action, documents when each process occurs, and provides for continuous updating. (See Figure 7-3.)
3. **Implementation/Use:** When the action plan is put in motion, all team members know each other's roles and actions. The family and the team have access to an electronic copy or (as necessary) a paper copy of their plan. The medical home team initiates and facilitates specific activities and interventions that lead to accomplishing the set goals. For example, they may convene a community team to establish a common intervention strategy, or a team member may reach out to a pediatric subspecialist to learn more about a condition in order to support comanagement efforts at the community practice level. Patients may participate in care skills building, and families may use relationships or links provided to connect to community resources and supports. Each action item in the plan includes goal-oriented time targets. Care and action plans serve as guides or scripts for the team's coordinating efforts, interactions, and monitoring. Planned follow-up visits provide the opportunity for measuring progress and keeping the plan current.
4. **Monitoring:** The medical home team gathers information about the activities, interventions, and services outlined in the action plan. Was the specialist referral appointment made and kept? What are the results? What subsequent tests were completed? What about other recommendations and needed resources? The team and family determine the effectiveness of care and services in reaching desired goals and outcomes, and what further steps are

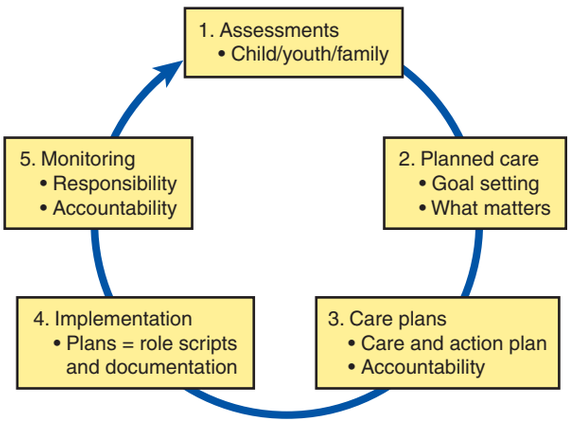

Figure 7-1 Shared plan of care: implementation with families.

Patient Name _____ Date _____

1) What would you like us to know about your child?
What does he/she do well? Like? Dislike? What matters to them?

2) What would you like us to know about you/your family? What matters to your family?

_____

3) Do you have any concerns or worries for your child? (Some examples below)

- ❑ Their growth/development
- ❑ Learning
- ❑ Sleeping
- ❑ Self-care
- ❑ Making and keeping friends
- ❑ Other (fill in): _____
- ❑ Doing things for themselves
- ❑ Falling behind in school
- ❑ Behavior
- ❑ The future
- ❑ Playing with friends

4) Have there been any changes since we saw you last, such as a:

- ❑ Brother or sister leaving home?
- ❑ Move to a new town?
- ❑ Sickness or death of a loved one?
- ❑ New job or job change?
- ❑ Separation or divorce?
- ❑ Other (fill in below)?

_____

5) Can we help you with any of the following needs?

- ❍ **Medical** (For example, help finding or understanding medical information; help finding health care for yourself or your family)?
- ❍ **Social** (For example, having someone to talk to when you need to; getting support at home; finding supports for the rest of your family)?
- ❍ **Educational** (For example, explaining your child's needs to teachers; help reading or understanding medical information)?
- ❍ **Financial** (For example, understanding insurance or finding help paying for needs that insurance does not cover-such as medications, formulas, or equipment)?
- ❍ **Legal** (For example, discussing laws and legal rights about your child's health care or their school needs)?
- ❍ **General.** Please let us know what else you need help with (if we don't know, we will work with you to find the answer)?

Notes:

_____

Figure 7-2 Pediatric care coordination assessment tool.

needed. Periodic check-in opportunities help the family-centered team maintain positive momentum. Assessments are refreshed, and changes are made to the plan with new needs and ideas incorporated. The action plan is the dynamic portion of comprehensive care planning and serves to provide proactive, preventive, and planned population care.

ACHIEVING THE FUNCTIONS OF CARE COORDINATION IN THE MEDICAL HOME

Many pediatricians have questioned how they can possibly provide all that comprehensive care coordination is meant to be within their medical home. Care coordination is a time- and resource-intensive service. A key strategy used by practices to help them coordinate care involves creating a designated practice role filled by someone who acts as a care coordinator. This staff person shares responsibility for coordination of care with the rest of the medical home team and family. The time required to redesign a system of reactive coordination of care into a more planned, proactive approach is time well spent. For example, a physician might see 2 or 3 more urgent patients during time realized through the use of a team member who is designated to perform cross-organizational communication and patient education. Many practices have redirected registered nurses from triage roles to provide population care, registry management, proactive patient and family assessments, education, and

Child's name: DOB: Parents/Guardians:
Primary diagnosis: Secondary diagnosis: Secondary diagnosis(s)

Original date of plan: Last Updated: / / / / /

1) Patient/Family Goal(s) 2) Clinical Goals	(1) (2)		
Main Concerns/Priorities	**Current Plans/Actions**	**Person(s) Responsible**	**Progress Date or Date Complete?**

Parent/Caregiver Signature: Clinician Signature: Care Coordinator:

Figure 7-3 Share plan of care: negotiated actions.

outreach. Others have used a social worker, family member, or other layperson familiar with community resources to help link families with needed supports and services.

Some practices are too small to afford a dedicated care coordinator position. In those settings, someone with at least partial responsibility can ensure that the practice is managing care coordination functions effectively. They might achieve this by distributing care coordination functions across various staff or by better utilizing any outside care coordination resources. In such situations it is important to articulate the intent to enhance the coordination of care and put a plan in motion to achieve team-based coordination. Links to resources to aid practices in this development, such as care coordination models, role descriptions, and related competencies, can be found in Tools for Practice at the end of this chapter.

A designated care coordinator fosters the delivery of family-centered services through a continuous cycle of assessment, goal setting, care planning, and follow-up. Someone in this role can help the team know families better, facilitate access to the team by being the point person in between visits, become an expert in community resources and government program eligibility, encourage family-to-family connections and supports, and build the team's capacity and ability to achieve its goals. A professional in this unique role must possess an array of key competencies and attributes. Smart hiring is important, as it takes a special person, passionate about the success of children and families, to provide excellent coordination of care. Fortunately, we now have new knowledge and tested tools to support these needs and indeed the development of care coordination as a standard of care.

DEMONSTRATING THE BENEFITS OF CARE COORDINATION

Measurement of ongoing progress can be achieved with activities like tracking the number of action plans in place or monitoring how care plan goals are addressed and met. Gaining direct family feedback about experiences and benefits is invaluable. Outcome measures can assess families' satisfaction with their use of care coordination. Many practices engage families as partners in their medical home improvement efforts. These families can guide and evaluate the developing role of the care coordinator. Families can also assist by speaking to the critical role care coordination holds in supporting them to raise, care for, and achieve optimal health for their children and youth.

A medical home team approach with fully developed care coordination services will also improve health and cost outcomes for children, youth, and families, and will increase the satisfaction of those receiving care. A number of studies have shown significant benefits related to implementation of care coordination models. These benefits include

- Achieved patient/family goals
- Reduced unmet needs
- Increased parent/caregiver social connectivity
- Improved patient/family satisfaction
- Improved communication among all stakeholders

Examples of cost outcomes include reduced hospital admissions, length of hospital stay, inpatient charges, and emergency department visits.

Creating patient-friendly experiences in the medical home also helps to create a favorable work environment that can lead to increased physician and staff satisfaction. Early adopters have addressed achieving care coordination with grants, collaborations, participation in demonstrations, data collection, and negotiation with health plans. While costly, developed care coordination activities align practices for health care reform activities and opportunities.

SUMMARY

Highly functioning pediatric medical homes, providing family-centered care and including flexible access, population approaches, and comprehensive team-based coordination, are emerging as a new standard of pediatric quality. A model of care coordination needs to be explicitly identified and shared—what, how, and for whom. Coordination tools such as assessments and goal-oriented care plans provide mechanisms for measurement and demonstration of quality. This is the future of pediatrics: the medical home, family partnerships, and well-coordinated team-based care.

TOOLS FOR PRACTICE

Engaging Patient and Family

- *Building Your Care Notebook* (Web page), American Academy of Pediatrics (www.medicalhomeinfo.org/for_families/care_notebook)
- *Emergency Information Form for Children With Special Needs* (template), American Academy of Pediatrics (www.aap.org/advocacy/blankform.pdf)
- *Hospital Stay Tracking Forms* (file archive), National Center for Medical Home Implementation (medicalhomeinfo.aap.org/tools-resources/Documents/Hospital%20Stay%20Tracking%20Forms.zip)
- *Partnering in Self-Management Support: A Toolkit for Clinicians* (Web page), National Center for Medical Home Implementation (www.medicalhomeinfo.org/how/care_partnership_support.aspx#self)
- *Pediatric Care Plan* (template), National Center for Medical Home Implementation (medicalhomes.aap.org/Documents/PediatricCarePlan.pdf)
- *Pediatric Specialists* (Web page), American Academy of Pediatrics (www.healthychildren.org/English/family-life/health-management/pediatric-specialists/Pages/default.aspx)

Practice Management and Care Coordination

- *APEX Digital Navigator* (practice transformation tool), American Academy of Pediatrics (www.aap.org/apex)
- *Improving Systems of Care for Children With Special Health Care Needs* (Web page), Lucile Packard Foundation for Children's Health (www.lpfch.org/programs/cshcn)
- *Measuring Medical Homes: Tools to Evaluate the Pediatric Patient- and Family-Centered Medical Home* (monograph), National Center for Medical Home Implementation (medicalhomeinfo.aap.org/tools-resources/Documents/Monograph_FINAL_Sept2010.pdf)

AAP POLICY

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Chapter 8
HEALTH LITERACY

Laura Shone, DrPH, MSW

INTRODUCTION

Definition of Health Literacy

Health literacy is defined by Nielsen-Bohlman and colleagues and Berkman, respectively, as the set of skills that "allow an individual to *obtain, process, understand, and communicate information about health; function in*

the health system, and make informed decisions during different phases of life." Health literacy is distinct from—yet often confused with—general (reading) literacy; this distinction hinges on context. General literacy describes the ability to "use printed and written information to function in society, to achieve one's goals, and develop one's knowledge and potential." In contrast, health literacy addresses these skills specifically in the context of navigating the health care and health insurance systems; using and understanding health information; managing health conditions, treatment and medicine use; and making health decisions—both individually and on behalf of others.

Health literacy problems interfere with an individual's ability to access and pay for medical care, understand health care advice, weigh the risks and benefits of health decisions, follow recommendations for treatment, use medicines safely and correctly, and understand rights and responsibilities in health care. People with limited health literacy face great difficulty in managing basic demands of the health system. However, health literacy is increasingly understood as a shared challenge and opportunity to balance the needs and skills of individuals with the complex demands of modern health care. However, health literacy problems extend beyond the health system itself. "People confront a complex and potentially overwhelming set of health messages every day," through health experiences and interactions, friends and family, the news and advertising media, and the virtual world of email and Web-based information from sources that range from reliable to dangerous. To manage disease, promote health, and prevent harm, patients need to make sense of the health information they hear, read, see, and experience in all of these contexts. An example of an encounter in which the health literacy level of the parent affects the health of a child is in Box 8-1.

Levels of Health Literacy

The 2003 National Assessment of Adult Literacy categorized 4 levels of health literacy: below basic, basic, adequate, and proficient (Figure 8-1). At the below basic level (14% of the US English-speaking population), individuals cannot use a bus or television schedule, understand an appointment slip, or complete medical paperwork—meaning that they have great difficulty just making or getting to a medical appointment. Although most US adults have basic (24%) or adequate (50%) health literacy, the demands of the US health care system more often require proficient skills. Everyday health behavior and decisions, use of the health system, and response to public health warnings increasingly require proficiency, yet only 12% of US English-speaking adults function at this level, with the skills necessary to understand and use medicolegal documents such as a consent form, medical release, or health care proxy.

Susan's case exemplifies one of many ways in which health literacy can affect pediatric care. Nationally, 30% of English-speaking parents have health literacy problems, yet this overall estimate can under-represent the scope and magnitude of specific challenges in pediatric care. When faced with scenarios in a national

BOX 8-1 A Case Study in Health Literacy

Susan's daughter had been ill for several days when she took her to the pediatrician. The doctor examined her daughter and diagnosed mild otitis media. He explained that this was probably caused by a virus, for which antibiotics are ineffective. Because parents are so used to receiving antibiotics for otitis, he was especially careful to explain why antibiotics were not necessary, assuring Susan that the baby would gradually get better over the next several days without them. He prescribed ear drops, and also recommended an over-the-counter analgesic to reduce fever and relieve pain. Finally, he reminded Susan to push fluids, reassured her that her daughter would be fine, and sent her to the drugstore. Several days later, the doctor received a call from the emergency department: Susan was there with her daughter, who was febrile, hyponatremic, and in obvious pain.

What happened? During the visit, the pediatrician recommended 2 liquid medicines, both to be administered as drops. At the drugstore, Susan filled the prescription and purchased acetaminophen liquid. Over the next several days, she gave the 2 medicines exactly on schedule; 1 by mouth and 1 in the baby's ears. She also forced her daughter to drink as much as she possibly could.

What went wrong? When Susan got home with the 2 medications, she knew that one was meant to be swallowed and one was meant to go in the baby's ears. With both medications in the same bag, she wasn't sure which was which, so she thought back to what the doctor had said. She knew that her daughter had an ear infection, and remembered that the doctor spent a lot of time talking about antibiotics. That made sense, because that's what you get for ear infections—antibiotics. She also knew that one medication was a prescription and the other was a "regular" medicine, that anybody could buy, to help with the pain in her daughter's ears. Well, that made it easier, she thought: the one for pain goes in the baby's ears, because that's where the pain is; and the prescription must go into her mouth because that's how you take antibiotics—you swallow them. Over the next few days, 3 things combined to send Susan and her daughter to the emergency department: she gave the ear drops by mouth and placed acetaminophen drops in her daughter's ears. In addition, because the doctor said to "push fluids," she wound up overhydrating her daughter to the point of hyponatremia.

What can be done? This case involves health literacy—but it is not just about Susan, it is about the health system as a whole and Susan's experiences within it, and it is about unfamiliar situations, multiple interactions, and the many places within the process where communication and understanding can break down.

Adapted from Abrams MA, Dreyer BP, eds. *Plain Language Pediatrics: Health Literacy Strategies and Communication Resources for Common Pediatric Topics.* Elk Grove Village, IL: American Academy of Pediatrics; 2009.

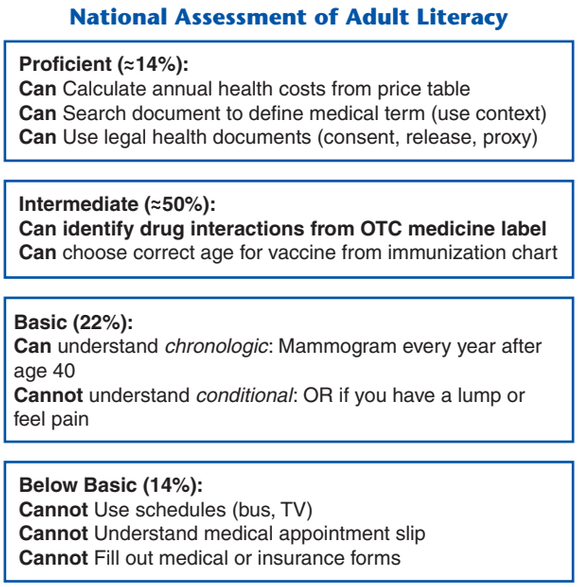
National Assessment of Adult Literacy
Proficient (≈14%):
Can Calculate annual health costs from price table
Can Search document to define medical term (use context)
Can Use legal health documents (consent, release, proxy)
Intermediate (≈50%):
Can identify drug interactions from OTC medicine label
Can choose correct age for vaccine from immunization chart
Basic (22%):
Can understand chronologic: Mammogram every year after age 40
Cannot understand conditional: OR if you have a lump or feel pain
Below Basic (14%):
Cannot Use schedules (bus, TV)
Cannot Understand medical appointment slip
Cannot Fill out medical or insurance forms

Figure 8-1 The 4 levels of health literacy from the National Assessment of Adult Literacy.

study, nearly 70% of parents could not correctly record basic information such as names or dates of birth on a health insurance form; 66% were unable to calculate the annual cost of a health insurance policy based on family size; and 46% were unable to perform 1 or more medication-related tasks.

It is impossible to gauge a parent's health literacy. Health literacy problems affect millions of people of all ages, races, income levels, and education levels, yet these problems are often hidden because adults with limited health literacy may feel ashamed of or conceal their struggles to read or understand material. These limitations have direct consequences for children, whose health care these parents are responsible for, as well as for the pediatricians who provide their medical care.

MEASUREMENT AND MANAGEMENT OF HEALTH LITERACY

Measurement science has been at the root of health literacy research: first, to describe the nature and prevalence of the problem, and then to monitor trends in prevalence and disparities over time and across subgroups. However, measurement of health literacy during routine clinical practice is seldom recommended. Instead, accumulated evidence provides strong rationale for the use of universal precautions for clear communication. Universal precautions will be discussed further throughout the chapter. However, because an understanding of measurement in the context of health literacy offers both context and rationale for the tools and strategies available to physicians, this section will provide an overview of measurement, including historically dominant tools, evolution of approaches to measurement, and emerging tools.

One way to better understand this otherwise invisible problem is to measure health literacy. The most common health literacy measurement tools have been developed and validated for adults, whereas few tools exist to measure health literacy in children. Most common measures assess 1 or more of the following: word pronunciation, reading comprehension (prose literacy), ability to understand numbers and perform basic arithmetic calculations (numeracy), and ability to derive meaning from context (document literacy). Newer tools have expanded to assess the performance of basic health tasks among parents, adolescents, and young adults. Examples of commonly used tools include:

- The Rapid Estimate of Adult Literacy in Medicine (REALM) and REALM-Teen: Both are 66-item word pronunciation tests, without context. Both take 2 to 3 minutes to administer 3 lists of words, and are scored by the number of words the participant is able to pronounce correctly. The cutoff scores are high because the test is meant to give all participants a positive experience: there are many easy words and a smaller number of words that are difficult. By design, most respondents can get more than half correct even if literacy is very limited (REALM scoring accounts for this). Because it is a word pronunciation test using English-language words, there is no equivalent in non-English languages. The Teen REALM has been validated for use in middle- and high-school-aged students (some "mature" words were replaced with word content more appropriate for children).
- The Short Test of Functional Health Literacy in Adults (S-TOFHLA) involves both reading and numeric calculation. Reading comprehension questions ask participants to choose from a list of words to complete the missing part of a sentence. For some, they look at a prompt and then respond. For others, they must choose from among multiple-choice options the word that makes the most sense. This measures ability to determine meaning from context. For the example, "your doctor has sent you to have a [blank] x-ray," the choice that makes the most sense is "stomach." This tool has a time limit of 7 minutes—most participants finish quickly, but all participants must stop at 7 minutes, whether or not they are done. There are different variations of this tool: the original TOFHLA (or "long" TOFHLA) takes approximately 22 minutes. The S-TOFHLA is limited to 7 minutes as described above. This tool is available in English and Spanish.
- The Newest Vital Sign (NVS) involves 6 questions about a nutrition facts label from a package of ice cream. Participants view a prop card containing the label and then answer 6 questions that are read by an interviewer. Examples of the questions include the following:
  - "If you eat the entire container, how many calories will you eat?"
  - "If you are allowed to eat 60 grams of carbohydrates as a snack, how much ice cream can you have?"
  - "If you are allergic to penicillin, peanuts, latex, and bee stings, is it safe for you to eat this ice cream?"

A score of 4 to 6 indicates adequate literacy; 2 to 3 indicates that literacy problems are possible; 1 to 2 indicates that literacy problems are likely. The NVS is also available in Spanish.

Evolution of Measurement and Emerging Tools

Measurement has continued to evolve toward more skills-based tools that address literacy and numeracy in simulated real-world task scenarios. Specific examples in pediatric health literacy include the Parent Health Literacy Activities Test (PHLAT). The PHLAT asks parents to act out or demonstrate what they do (or would do) in several scenarios common to child health, such as dispensing and administering a dose of liquid medicine using label instructions and dosing instruments. This evolution toward more pragmatic and comprehensive measurement approaches is particularly important for underserved parent, adolescent, and young adult populations because more reading-focused instruments can produce high scores that miss the chance to identify low numeracy.

There has been some concern that use of screening tools in clinical settings could cause embarrassment for children, particularly for those who have literacy problems. At the same time, most participants in one study reported no shame (99%) from screening with the NVS. Measurement among a sample of patients within a practice can provide practice-level estimates of health literacy to inform decisions about practice-level strategies and to become a more health-literate practice; however, routine measurement of health literacy for individual patients at visits is not recommended.

A Universal Precautions Approach

One alternative to measurement in clinical settings is the use of strategies for clear communication in clinical practice. The Agency for Healthcare Research and Quality (AHRQ) encourages physicians to use universal precautions for health literacy—to employ evidence-based techniques to communicate, clarify, and confirm information in clinical care. Because it is impossible to tell which patients have problems with health literacy (and because only those who have proficient skills can manage most health situations), the universal precautions approach encourages use of the clearest communication possible *with everyone* at all times.

In Susan's case, the stress of parenthood, sleeplessness, and having a sick baby may have been factors, yet other life stresses can also play a role. This phenomenon extends to staff and others in the practice; if only 12% of adults have proficient health literacy, that leaves 9 of every 10 English-speaking adults with some degree of health literacy problem. Furthermore, stress can compete with the ability to focus and therefore interferes with the ability to understand medical information that may otherwise seem routine or simple. Stress does not discriminate: those who work in the practice are as likely as patients to be included in this group. Some individuals may struggle routinely, whereas others who function well under normal circumstances may become confused when dealing with a stressful, traumatic, or unexpected medical event. Pediatricians may not always know what other stresses a family, staff member, or colleague may be facing; therefore, practicing universal precautions for clear communication with everyone can minimize confusion and enhance patient–physician experiences.

Universal precautions can include the use of pictograms to represent information visually as well as verbally; the use of techniques like teachback, whereby the pediatrician or nurse asks a patient to teach back to the physician the information or action just described; or Ask Me 3, which involves teaching new communication skills to empower patients.

Teachback

One of the most useful and important universal precautions techniques is *teachback*. In teachback, the physician literally asks patients to teach back, or walk through, the treatment or process the physician just described. Teachback is iterative, with each participant confirming and clarifying points of confusion or misunderstanding, until the physician and the patient are able to describe the information to one another in the same way. For example, when a new medicine is prescribed, pediatricians can enhance patient and parent understanding by demonstrating how the medicine should be used and then asking the patient or parent to teach back the process or steps as they understood them.

The purpose of teachback is twofold: it is confirmatory for the physician and identifies when information should be clarified or repeated; and, for the patient, the experience of teaching new information or a new process back to the physician helps to move information from working memory to long-term memory and thus enhance comprehension. Demonstration and teachback can be particularly useful in ensuring patient adherence and safety with new treatments or medicines, particularly if dosing instruments or equipment such as a spacer or inhaler are required. Teachback can also be used to confirm that patients understand the risk and benefits of different treatments or health choices.

Ask Me 3

Pediatricians can also empower parents and patients to facilitate their own understanding. The Ask Me 3 method teaches patients to ask 3 questions at every health visit:

1. What is my main problem?
2. What do I need to do?
3. Why is it important for me to do this?

Along with routine use of teachback, pediatricians can teach parents and patients together to use these questions, and—over time—can model and reinforce patients' growth in their use of Ask Me 3 until it becomes second nature. Teachback and Ask Me 3 are highly complementary, with patients and physicians teaming together to enhance communication, understanding, adherence, and safety.

HEALTH LITERACY IN PEDIATRIC PRACTICE

Pediatricians are becoming more aware of health literacy and the importance of responding to communication challenges in health care, yet their use of evidence-based techniques in office practice is limited.

To help encourage the practice-based use of evidence-based techniques, AHRQ has produced a comprehensive toolkit, which is available on the Internet at no cost (see Tools for Practice at the end of this chapter). It includes video case examples like Susan's; examples of patient materials such as pictograms for medicine use and asthma action plans that can be adapted for specific needs of an individual practice; and quality improvement tools to assess the practice and identify opportunities for practice change.

Links to these and other resources, including toolkits of patient materials to support practices in implementing these methods, are included in Tools for Practice at the end of this chapter.

During the past decade, a wide range of interventions have demonstrated some success in improving medication adherence, management of chronic illness, understanding of specific health information, and ability to safely complete specific health tasks. Although most of these interventions have been conducted in adults, evidence for the importance of parent health literacy in caring for children is mounting. There is also increasing interest in exploring potential developmental links between parent or caregiver health literacy and child health literacy. As the field of health literacy expands beyond its original exploration of age-related cognitive decline to encompass parents, children, and adolescents, it is beginning to incorporate health literacy *development* in addition to health literacy *decline*. Health literacy in pediatric care therefore becomes an opportunity for learning and growth for parents, children, and pediatricians.

Health Literacy and Parents

As Susan's case illustrates, a parent or caregiver's health literacy skills affect that individual's ability to make health decisions for a child. Studies have linked health literacy problems among parents with poorer health outcomes among their children, finding the most dramatic effects among young children. Parents who have health literacy problems may be unable to correctly administer medicines to children using dosing instruments and consumer medication information (ie, package inserts or label instructions); may struggle to understand written material, including medical forms and schedules for recommended visits, immunizations, or preventive screening; and may have difficulty managing a child's chronic health conditions such as asthma or diabetes.

Medicine packages routinely contain confusing, incomplete, or incorrect information about how to administer a dose of medicine for a child. One study of measuring devices and label instructions for the top-selling liquid medicines for children found that in 98.6% of cases, the dosing instruments and label instructions were inconsistent, particularly for units of measure and recommended dose. Such problems include missing markings, extraneous markings, atypical units of measurement, and use of different units of measurement on the device and on the label instructions (eg, label indicates teaspoons, whereas measuring device is labeled in milliliters). Although this example comes from a study of labels on 148 liquid medicines for children, labels on all prescription drugs can be equally unclear, inconsistent, and confusing for patients. As the Safe Use Initiative of the US Department of Health and Human Services and the Food and Drug Administration undertake efforts to address labeling issues, efforts to support and enhance parents' skills continue to advance. In a small but growing body of evidence, interventions to address health literacy of caregivers, or of children themselves, have shown promise in helping caregivers learn to better understand written materials such as consent forms and vaccine information, improved management of asthma, and reduced errors in administration of liquid medicines to children.

Health Literacy and Children

Pediatricians should recognize the health literacy needs of parents but should also consider the development of health literacy in children. Developmental theories support the ability of children and adolescents to develop health literacy skills through age-appropriate information and experiences. One conceptual model frames health literacy in a developmental context as *health learning capacity*. This framework synthesizes evidence from the fields of education, cognitive science, and psychology into a constellation of cognitive and psychosocial skills that can be learned and are needed to "promote, protect, and manage one's own or a child's health."

Ideally, health learning builds cumulatively. Health awareness develops throughout childhood and early adolescence; knowledge, experience, and independence in making decisions build during middle and late adolescence; and increasing autonomy and responsibility culminate in self-management of health among young adults. Evidence about cognitive development supports this progression: from basic or functional skills (concrete operational), to the development of interactive skills (formal operational), and finally to the maturation of executive function (the ability to plan, reason, apply logic, problem-solve, generalize, and apply information in new situations).

Framing health literacy in this developmental context allows delineation of potential roles for the pediatrician to enhance health learning through experiences for both parents and patients. Physicians can teach, model, role-play, rehearse, and reinforce key health concepts, skills, and processes during regular health care encounters. In turn, both parents and pediatricians can do the same to encourage health learning in children and adolescents. At the end of this chapter are resources that pediatricians can use to address and ameliorate health literacy problems in pediatric practice.

SUMMARY

Every interaction between patients and physicians or individuals and health systems shapes the health literacy of parents, their children, and ultimately society. Using the techniques and resources described in this chapter, pediatricians can take tangible steps to alter these interactions. Health literacy problems compromise every aspect of individual health, medical care, and health outcomes and influence health-related interactions within and outside of a practice. Health

literacy is a clinical, public health, ethical, and disparities issue; for this reason, the US Department of Health and Human Services has highlighted health literacy as national health priority. As highlighted by Dr. Rima Rudd, although providers "can do little to improve literacy skills of the public, they can re-examine their own activities, assumptions, and [practice] environments to remove literacy-related barriers." The pediatric community is a critical constituent in these and other efforts to improve communication, enhance patient safety, simplify health systems when possible, and foster the development of health literacy skills in parents and patients.

TOOLS FOR PRACTICE

Engaging Patient and Family

- *Ask Me 3* (Web site), National Patient Safety Foundation (www.npsf.org/?page=askme3)
- *What Is Health Literacy?* (fact sheet), Pfizer (www.pfizer.com/health/literacy/patients_and_families)
- *What to Do* for Health (books), Institute for Healthcare Advancement (www.iha4health.org/our-products)

Medical Decision Support

- *Attributes of a Health Literate Organization* (booklet), Brach C, et al; Institute of Medicine (www.iom.edu/~/media/Files/Perspectives-Files/2012/Discussion-Papers/BPH_HLit_Attributes.pdf)
- *FDA Safe Use Initiative: Collaborating to Reduce Preventable Harm from Medications* (booklet), US Food and Drug Administration (www.fda.gov/downloads/Drugs/DrugSafety/UCM188961.pdf)
- *Health Literacy: A Prescription to End Confusion* (book), National Academies Press (www.nap.edu/catalog.php?record_id=10883)
- *Health Literacy Resources* (Web page), Centers for Disease Control and Prevention. (www.cdc.gov/healthliteracy/Learn/Resources.html)
- *Health Literacy* (Web page), American Medical Association (www.ama-assn.org/ama/pub/about-ama/ama-foundation/our-programs/public-health/health-literacy-program.page)
- *Health Literacy Universal Precautions Toolkit* (toolkit), Agency for Healthcare Research and Quality (www.ahrq.gov/professionals/quality-patient-safety/quality-resources/tools/literacy-toolkit/index.html)
- *The Medical Library Association Guide to Health Literacy at the Library* (book), the Medical Library Association (www.alastore.ala.org)
- *National Action Plan to Improve Health Literacy* (booklet), US Department of Health and Human Services Office of Disease Prevention and Health Promotion (www.health.gov/communication/HLActionPlan/pdf/Health_Literacy_Action_Plan.pdf)
- *Plain Language Pediatrics: Health Literacy Strategies and Communication Resources for Common Pediatric Topics* (book), American Academy of Pediatrics (shop.aap.org)
- *Plain Language Principles and Thesaurus for Making HIPAA Privacy Notices More Readable* (booklet), US Department of Health and Human Services (www.aspiruslibrary.org/literacy/MakingHIPAAPrivacyNoticesMoreReadable.pdf)
- *Proceedings of the Surgeon General's Workshop on Improving Health Literacy* (booklet), Office of the US Surgeon General (www.ncbi.nlm.nih.gov/books/NBK44257/)
- *What Is Clear Health Communication*? (Web page), Pfizer Inc. (www.pfizer.com/health/literacy/healthcare_professionals/overview_of_health_literacy_health_communication/what_is_clear_health_communication)

SUGGESTED READINGS

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Chapter 9

PARTNERING WITH FAMILIES IN HOSPITAL AND COMMUNITY SETTINGS

Ruth R. Walden, MSW; Molly Cole

During Nick's childhood he was seen by a series of orthopedic surgeons; neurologists; other pediatric specialists; nurses and nurse practitioners; and physical, speech, and occupational therapists. This rotation of health professionals is the norm for kids like Nick. But we have always been there, bringing him home from the hospital in a full-body cast, hosting birthday parties, learning to deal with his seizures, trying out new wheelchairs or computers, modifying our work schedules, teaching him to swim, remembering medicines, helping with homework, finding an accessible summer camp.

When our family moved . . . our pediatrician offered to continue to follow Nick and his siblings. But he also encouraged us to visit a nearby rural primary care clinic. [Our doctor] and his clinic staff grew to know and understand Nick and his changing diagnoses. We became comfortable at the clinic, dropping in before dinner for a quick consultation or to check blood levels. For 12 years Nick's schools trusted [his] experience and routinely followed his guidance about therapy and nutrition routines.

Knowing that Nick's primary providers were nearby supported our determination to care for him at home—a determination inspired by a pediatric movement called family-centered care

that probably prolonged his life. In family-centered care, professionals . . . and families like ours build a partnership of trust that helps us make joint decisions. Together we connect the science of medicine with the evidence of daily life. This kind of care returned to my husband and me a sense of control over Nick's fragile health.

—POLLY ARANGO, "A PEDIATRIC REVOLUTION AT HOME." FROM *HEALTH AFFAIRS*, SEPTEMBER 2004

Parenting a child with special health care needs and disabilities can be challenging and rewarding. Parents are faced with accessing care and services from multiple health care specialists; allied health services such as occupational, speech, and physical therapy; multiple public and private payment sources; and early intervention school programs and family support programs. Success hinges on the critical ability of parents to partner with their primary care physician (PCP) in developing and implementing a care plan that addresses the unique needs of their children. The collaboration of the physician and the family promotes optimal health for the child. The chief tenets of collaborating well with families are outlined in Box 9-1.

FIRST CONTACT: SHARING UNEXPECTED NEWS

For a pediatrician, sharing the news with parents that their child has a special health care need may be a difficult and complex process. (For detailed guidance, please see Chapter 49, Discussing Serious Symptoms, Results, and Diagnoses With the Patient and Family.) Physicians' choice of words, willingness to listen and answer questions, and empathy and support at this time are a critical foundation to building a lasting and trusting relationship with families who may need ongoing and more specialized care within the practice. Just as the job of the PCP for this child's unique needs is only beginning, when the parents receive this information, their job is only beginning as well. A parent's first challenge is sharing the information with other family members, including other siblings, the spouse, extended family, and friends in the community. Having complete information in a way that family members can understand it and share it becomes critical for them. Even more challenging, parents must then incorporate their child's unique health care needs into the context of their family's hopes, dreams, strengths, and challenges. They must make tough decisions based on their family's priorities and goals. Providing the family with adequate information to make these decisions and respecting choices that families make are important factors, provided the child's life is not at risk.

To assist parents through the journey of caring for their child, the pediatrician's focus needs to be on building a strong partnership with the family. Creating a trusting relationship, built on mutual respect, and valuing the parents' knowledge about their child, takes time and requires an initial meeting that is calm, focused, and free from distractions in a safe and supportive environment. Interruptions should be limited, and the PCP must make sure that the location is private and comfortable. The family should be given some warning of difficult news so that they have time to bring in other family members or other supports. Many parents will state that the most difficult experience for them is not hearing the news, but rather being faced with the task of sharing it with their children and other family members and trying to answer their questions. If only a single caregiver is present, then a time should be arranged to speak by telephone to the other family members. The PCP should help both parents think about ways to explain this situation to other children and, if possible, should talk to these other siblings as well. Brothers and sisters of a child with special health care needs often report that they felt left out of the care of their sibling. Their questions should be answered and suggestions should be given on how to be involved.

In many instances, when difficult news is shared with families, they hear only the first few words, becoming

BOX 9-1 Guide to Collaborating With Families

1. Respect parents for their knowledge and understanding about their child and their ability to relate to their child.
2. Accept the parents, and later the youth, as full and equal partners in the child's care. The primary care physician and both parents, and, later, the older child, all working together, will be powerful champions to obtain the best results.
3. Always take the time to listen to parents and the child. Their words and actions will reflect their emotional status and provide an opportunity to learn what their wants, desires, and hopes are for their child.
4. Learning about the meaning of the child's illness or condition is important to the parents because this information will explain their actions, reactions, and goals for their child and responses to changes in their child's condition or treatment recommendations. Give the family as much information in as understandable a format as possible. Families need this information in order to partner effectively with physicians; they also need to be able to communicate about their child's condition with their own support network of families and friends.
5. Keep the child as the center of focus.
6. If care coordination cannot be provided in the primary care physician's practice, then the parents should be referred to outside sources of support.
7. Early in the relationship with the family, discuss the fact that disagreements will occur. Make an arrangement to respect each other's judgment and to agree to disagree.

so distracted or anxious that they miss much of what is said. For the health professional, listening is a critical part of this exchange. The PCP must ensure that the family members' questions are answered, and maintain enough patience to answer them repeatedly. The ability of the PCP to be available to answer calls from the family, and to check back with family members to see how they are doing is important. Parents may seem to be in denial because they have not fully absorbed the complexity of their child's health condition.

Once a family has had time to absorb the information, share it with other family members, and ask questions, the time comes to make referrals for other community supports, such as early intervention programs, family support groups, or other evaluations and treatments. These referrals should be part of a care coordination plan, developed with the family, to ensure that the plan addresses the family's concerns and answers all questions. In this partnership, the care coordination plan will be the tool to ensure that the pediatrician's and the family's priorities are addressed. The referrals outlined in this plan are a mechanism to make sure that all the needs of this parent-professional partnership are addressed. During follow-up visits, parents can report what is happening in the early intervention program, school program, or family support program, and they hear results of the pediatrician's examinations, tests, and other medical referrals. Thus, the basis of the partnership—mutual respect for the knowledge, skills, and experience of both the parent and the physician—is in place.

Supporting the family through even relatively simple decisions may be necessary. Specialist referrals are a decision point that should be reached in partnership with the family. The PCP should listen carefully to the parents as they explain their needs or concerns and address them in a sensitive and caring manner. Although parents may be overwhelmed, their concern for their child drives all that they do. Unless the family's choices will have a negative outcome, pediatricians must try to empathize, putting themselves in the family's place before responding.

OFFICE VISIT

Scheduling an office visit for a child with special health care needs can be a positive experience if a few accommodations are made. The child's record should be flagged to indicate if the child needs extended time for the appointment or if the child may need to be seen immediately on arrival to accommodate any special needs. The appointment should be scheduled at a time of day that will be easiest on the child, such as the first thing in the morning, at the end of the day, or right before or after lunch. Although many patients request these times, legitimate reasons exist for a child with special health care needs to be seen at a time that is best for him or her. Family centeredness is important. (See Chapter 6, Medical Home Collaborative Care.) Allowing for cultural differences is essential to ensure an optimal visit. (See Chapter 48, Providing Culturally Effective Care.)

The office visit should not consist only of milestones and physical examination, but also allow for dialogue to learn about the child. Getting to know the child and observing how the child interacts are important tasks. Having the family report on how the child plays and relates to the environment and how the child is doing socially is important, because these interactions may be different from those of the typical child. The parents should be engaged in full partnership because they are the experts on their child. They know the child's likes, dislikes, behaviors, and abilities. Family members may need additional time for questions to be answered and concerns to be addressed. If possible, the child should be engaged in the discussion about his or her own health and asked about any concerns or questions. Writing out instructions for changes in routine or new medications and how they are to be taken is helpful. If an electronic medical record is used in the pediatrician's office, it is helpful to provide the parent with an electronic personal health record for their child, which can be shared with specialists and other allied health care providers and updated frequently. There should be a standardized, routine process for communication among the PCP, specialists, mental health professionals, therapists, teachers, and anyone else, in order for the medical home team to function well. The PCP should check to be sure that the family understands the recommendations and that questions are answered before leaving the office. The nurse, social worker, or health educator may be able to provide the explanations for the families. Translation may be needed for family members who speak a different language. The need to assess the emotional status of the family, including the siblings, should be emphasized during the visit. Parents should be referred to the directory of State Title V Programs at their state's department of health, to Family Voices, Inc. (www.familyvoices.org), and to the local MUMS National Parent-to-Parent Network (www.netnet.net/mums) to provide avenues for exploring funding of services and sources of emotional support and advocacy. These programs can also provide matching with families whose children have the same diagnosis.

The child with special health care needs often requires emergency services from the office or the hospital. The PCP should check with the family to see if they have an emergency plan in place. The American Academy of Pediatrics and the American College of Emergency Physicians have developed an emergency form that can be completed and updated by the physician. Copies should be kept with the parents, with pediatricians, with the child's car seat or diaper bag, and in school. This document will prepare the emergency physicians and hospital staff to best meet the needs of the child because it will provide baseline information. This sheet is used in collaboration with a MedicAlert bracelet or tag. Parents should be urged to contact their local ambulance company to introduce their child and to help avoid misunderstandings when an emergency arises. Also important is knowing if the local community hospital is equipped to handle an emergency for the child or if the tertiary care hospital is best suited to deal with the child's condition. The parents should also be advised whether they should contact the office in an emergency or on arrival at the hospital. The parents, if they choose, should be permitted to stay with their child during emergency procedures, including resuscitation. The PCP may be able

to influence the hospital staff to support the family's choice. Parents may need support and care coordination during and after the emergency situation.

Many children with special needs require home care. Discharge planners may initially plan for the home care, but the PCP must follow up, complete the paperwork, and direct and coordinate the care. Families should be assisted throughout the process. The PCP should periodically check with the family to ensure consistency and quality of care. Home care agencies are often understaffed and cannot provide consistent care for the child. Parents should be trained to care for their children at home but should be advised to also care for their own mental health. The PCP should note that having outsiders who come into the home and intrude on family life is a burden on the entire family. Supporting the family members through this process and referring them for training on how to deal with the home health caregiver can be helpful. If the parents need financial assistance to access the home care, then referral to the Katie Beckett Medicaid waiver program or other public financing programs in their state should be made. Parents can contact the Title V Program in their state, which is prepared to direct them to the agency directing the waiver program for their state.

Early intervention, preschool, and school services are significant milestones for any child but particularly for the child with special health care needs. Parents often know the type of setting they want for their child; they understand their child's learning style and have a feeling for the type of experience that will work to make the child's formative years most productive. The physician may be asked to partner with the family to find the most appropriate placement. School placement decisions should include benefits for the child and the class as a whole. Modifications and the services of a special education teacher can lead to positive outcomes not just for the child with special health care needs, but also for the other children in the class who learn to accept people who are different. However, if parents choose a less inclusive setting in a special class, then their decision should be honored.

Information about the child's clinical needs will help in the development of the best program for the child, regardless of the placement choice. Forms for specific services (occupational, physical, and speech therapies among others) will be required. If possible, attending or participating by telephone in the school placement process is desired. Parents should be asked to envision what they see their child doing in 18 years. Transition to adult living, earning, and learning should take place from birth through adulthood, understanding that the child may go through many changes within that time. The physician is a role model for the family for advocating and championing the needs of the child. As an equal partner with the family, the PCP may be required to advocate with other physicians, insurance companies, and the educational system.

SUPPORT DURING HOSPITALIZATION

Hospitalizations, whether planned or resulting from an emergency, are stressful times for families who have a child with special health care needs. In the emergency department (ED), the hospital staff must engage the parents as partners in addressing the crisis at hand. The emergency plan developed with the family will assist the hospital staff in providing a smooth ED experience. When contacted by the ED physician, the child's health professional can assist in this process by providing the staff with insight into the parents' ability to report on their child's needs accurately and encouraging the staff to use the parents' input during their ED stay.

For a planned hospital admission, the parents must have a clear understanding of the usual information: the purpose of the admission and what is expected to happen during the time the child is hospitalized, potential challenges, and anticipated discharge. However, for a child with special health care needs, other considerations must also be addressed: special beds, seating, diets and feeding needs, specialized activities with the child life department or volunteers, communication problems, and behavior concerns. Parents should be encouraged to develop a list of their child's unique care needs and bring the list with them so that these points can be easily incorporated into the care plan with hospital staff.

Many parents who have a child with special health care needs prefer to stay in the hospital to ensure that their child's unique needs can be met. Some parents cannot be available for long periods because of other commitments. In either case, the PCP is critical to the development of a strong working partnership between the family and the hospital staff. Parents have unique insight and understanding about their child's care needs, and the staff should be encouraged to seek their input during the hospital stay. The PCP should encourage the staff to schedule times to meet with caregivers, whether they stay at the hospital or not. Parents must be allowed to be present during procedures. The staff should be encouraged to work with the parents and to incorporate the parents' knowledge about their child's unique care needs into the hospital care plan.

Teaching hospitals pose opportunities and challenges. Parents should be encouraged to be present during rounds ("family-centered rounds") and should be treated as a critical component of the child's hospital care team. Not only will this practice enhance outcomes for the child, but it can also be a good teaching tool for residents and other students in teaching hospitals. The PCP should model this partnership.

One of the usual learning opportunities in a teaching hospital is the practice of taking the child's history. Parents who have a child with frequent hospitalizations may find that this process of medical history taking, although a valuable teaching tool, is painful and stressful. Recalling traumatic and difficult events in their child's medical history at a time when their child is again being hospitalized is something that some parents will resist, and they may need support when they decline to participate in this process, if it is not critical to the treatment.

Parents often anxiously await the arrival of the PCP at the hospital each day. The PCP is their partner in their child's care, and they look for daily insight, support, and information. PCPs should let family members

know when they will be in the hospital and available to talk. If the physician and parents fail to connect, the PCP should check in with the parents by telephone later in the day so that any of their questions can be answered and so they can be updated on their child's status.

Parents must be involved in discharge planning—from a discussion of wellness and stability to the types of supports they may need at discharge. If their child's care needs have changed as a result of this hospitalization, then the team needs to ensure that the parents are trained on any new treatment methods or equipment, and that they have adequate support at home. The PCP should assist the team, including the family members, in the discharge process. Issues such as school, accessibility, nursing, equipment, medications, and follow-up with the PCP and other specialists are part of the process. Additionally, the care coordination plan developed by the PCP and the family may need to be modified.

On the day of discharge, the discharge planner or other hospital staff members usually meet with the family to review the discharge plan. The PCP should review the discharge plan either on the day of discharge or at an office visit after discharge. The parents should be comfortable with the treatments, needs, and follow-up appointments, especially if any changes in care have occurred as a result of this hospitalization.

TRANSITIONS

Early intervention programs provide a nurturing and supportive staff and an environment for the child with special health care needs and the family. Services are focused on the child and are family centered. Programs are much less supportive when the child moves to the early childhood program within the child's school district. Services may be fewer than they were in the early intervention program; family supports may end completely or become less family centered. For many children, this move will also mean the transition from home-based to center-based services. Parents should be made aware of these differences and be supported during this potentially difficult transition. Referrals for other services through the Title V Program in their state and community agencies may become necessary to supplement the Individuals with Disabilities Education Act, Part B, Preschool Grants Program. The PCP may need to check with the parents to ascertain their needs more often than usual during this transition.

The transition from the smaller setting of the early childhood program to the elementary school program can be frightening for the family and child. How will the child be accepted? How will the staff meet the child's needs? Are the allied services going to continue to support progress? Is the child placed with the best teacher to meet the child's learning style? These questions are a few that the parents may have as they approach the beginning of school. During the school physical, the PCP may need to reassure the family. The PCP may agree or disagree with the placement, but the support will help the family approach the beginning or continuation of the program with less apprehension. Understanding and empathy will help the family.

Transition from elementary to middle and then from middle to high school may bring placement changes and insecurity to the child and family. Friends who have surrounded the child up to this point may not be available to support the child; teachers and staff will be new and perhaps less supportive and understanding of the child's needs. Providing clinical information, and clearly and concisely explaining the needs of the child may be necessary. The PCP should check with the parents to determine their needs and to see how smoothly the transition is proceeding.

Transitions occur at other junctures as well. An illness may result in changes in the child's ability to attend school. A child with a terminal illness may deteriorate for long periods, and the school personnel may not understand the need to adjust their demands of the student. This circumstance may be more characteristic of middle and high schools because of the more rigorous nature of the curricula. The physician's support of the family and staff within school will help increase understanding, reduce demands and expectations, and support the child or young adult through the illness. If the illness is one that results in physical or cognitive deterioration, then preparing the family and, if the parents wish, the educational program, for the changes is important. These transitions can be sources of great stress not only for the parents, but also the siblings and extended family members. Helplessly watching as the child's ability diminishes over time is difficult. Gently providing support and referrals for emotional and family support and services is critical.

The transition to adult health care takes planning and time for the PCP, the adolescent, and the family. Preparing the adolescent for an adult health care physician who may be less family centered requires advocating, sharing of information, mentoring the adolescent, and relying on the trust of the family. This preparation is a lifelong process of focusing on a vision for the future and developing the skills to achieve that vision. Choosing an adult health care physician should be an informed decision of the partnership: adolescent, parents, and PCP. Often a med-peds trained physician has the knowledge and experience to care for an adult with special health care needs originating during childhood. Preparing the new physician is the responsibility of the physician and parents. Adolescents should be empowered to speak on their own behalf, to describe their condition, to share how it affects them daily, and to seek care for themselves. The mentoring should begin early and continue until such time as the PCP discharges the adolescent from care.

FINANCIAL CONSIDERATION

The parents may face significant unpaid bills, difficulties with getting insurance to pay for services, insurance companies reversing decisions, and the need to seek services that may be difficult to find locally. Referrals to the state insurance program, Medicaid for children, or Medicaid waiver programs if the family does not have insurance may assist families. If the physician's office does not accept these sources of payment, then helping the family identify a practice that does will also be helpful if the parents are not able

to afford the associated out-of-pocket expenses. Displaying brochures about the state insurance program and Medicaid within the physician's office will draw the attention of parents needing these services.

END-OF-LIFE PLANNING

When caring for a child who has a terminal diagnosis, the PCP must have discussions with the family at a time other than when the child is in crisis. Included in this meeting should be a frank discussion of the family's wishes regarding do-not-resuscitate orders. (See Chapter 67, Palliative, End-of-Life, and Bereavement Care.)

CONCLUSION

Parents seek physicians who are able to treat them as equal partners in the care of their children. They are looking for someone who will be nonjudgmental as long as the child is safe, well cared for, and treated with respect. The PCP needs to coordinate the care provided to the child with special health care needs by collaborating effectively with the various professionals involved in the child's care. Parents will respect the PCP who admits to not knowing but who will seek out the answer or the specialist who does know. Parents will respect the PCP who can provide sensitive, nurturing, and supportive care.

> *". . . Families are visionaries. Their dreams are not tied to bureaucratic limitations. Their ideas and hopes for their children, their families, and their communities provide challenge, inspiration, and guidance."*
>
> (Elizabeth S. Jeppson and Josie Thomas, *Essential Allies: Families as Advisors,* Institute for Family Centered Care, 1995)

TOOLS FOR PRACTICE

Community Advocacy and Care Coordination

- *A Patient and Family Advisory Council Work Plan: Getting Started* (form), Institute for Family-Centered Care (www.ipfcc.org/pdf/PDF/advcouncil_workplan.pdf)
- *Creating Patient and Family Advisory Councils* (booklet), Institute for Patient- and Family-Centered Care (www.ipfcc.org/advance/Advisory_Councils.pdf)

Engaging Patient and Family

- *Pediatric Care Plan* (form), American Academy of Pediatrics (medicalhomes.aap.org/Documents/PediatricCarePlan.pdf)

Practice Management and Care Coordination

- *Coding for Medical Home Visits* (Web page), American Academy of Pediatrics (www.aap.org/en-us/professional-resources/practice-support/Coding-at-the-AAP/Pages/Coding-for-Medical-Home-Visits.aspx)
- *Measuring Medical Homes: Tools to Evaluate the Pediatric Patient- and Family-Centered Medical Home* (monograph), National Center for Medical Home Implementation (medicalhomeinfo.aap.org/tools-resources/Documents/Monograph_FINAL_Sept2010.pdf)
- *Patient- and Family-Centered Ambulatory Care: A Checklist* (handout), Institute for Family-Centered Care (www.ipfcc.org/advance/topics/Ambulatory-Care-Key-Concepts.pdf)

AAP POLICY

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Institute for Family-Centered Care. Resources. Available at: www.familycenteredcare.org/resources/index.html

Kids As Self Advocates (KASA): Teens and young adults with special health care needs speaking on our own behalf. www.fvkasa.org

The Family Village. A Global Community of Disability-Related Resources. Available at: www.familyvillage.wisc.edu

Chapter 10

FAMILY-CENTERED CARE OF HOSPITALIZED CHILDREN

Jerrold M. Eichner, MD

With the growth of the hospitalist movement has come a change in the organization of inpatient services. The patient- and family-centered medical home, or simply medical home (MH), is an approach to providing comprehensive primary care to children, youth, and adults. The primary care physician (PCP) is responsible for meeting the child's health care needs or appropriately arranging care with other qualified professionals. This may include hospitalists to meet the care needs of the child while in the hospital, although many times the PCP may not be able to choose the hospitalist because admissions to hospital are often through an emergency department or other urgent care setting. In the hospitalist model, the shift of responsibility for the patient during the inpatient stay from the MH and the PCP to the hospitalist has placed on both parties a burden of responsibility to ensure the continuity of care for the

patient. Research indicates that ineffective communication between the 2 types of providers on many levels can adversely affect patient care and safety. Differences in the attitudes of community pediatricians toward hospitalist programs vary widely and include significant concerns about communication. Successful communication between hospitalists and PCPs is an essential component of effective hospitalist medicine and a necessary way of avoiding interruptions in patient care. The collaborative relationship between these physicians ensures a smooth transition of patient care from the inpatient to the outpatient service, and vice versa. Support for the continuity of care facilitates a global understanding of the patient and assists in appropriate diagnosis and initiation of inpatient therapy and effective outpatient follow-up. This deeper understanding allows each physician to consider more effectively the effect of social, financial, and other factors that are unique to each patient's personal history.

Patient- and family-centered care recognizes that important role of the family in the patient's life. Most of the time, the child and family have established a working relationship with the PCP and the MH for the care of the child. They play an integral role in the health care team and participate in health care decision making. Temporarily transferring that relationship, even for a short time as an inpatient, is important in the continuity of family-centered care while the child is hospitalized. Including families in decision making and keeping them informed of their child's progress are as important in the hospital as they are in the outpatient setting. Family-centered hospital rounds enhance the exchange of information and encourage families in decision sharing.

COMMUNICATION BETWEEN PRIMARY CARE PHYSICIAN AND HOSPITALIST

The PCP's knowledge and insight are critical in providing the best care for the patient. The hospitalist has the skills to provide care for the hospitalized child that the PCP does not and is the one to make appropriate use of diagnostic tests, consultations, and treatments in the hospital. The communication between the PCP and the hospitalist at the time of admission should include the pertinent medical information (past history, prior investigations, consultations, prior therapeutic interventions, etc) as well as the wishes and plans of the family. This information often can be provided only by the patient's PCP. This is particularly important in the care of children with chronic disease and special health care needs. These factors are instrumental in preventing interruptions in care, making critical decisions such as end-of-life care, suggesting social service interventions, and recognizing the value of specialty services for patients with special health care needs. Similarly, hospitalists may have knowledge of repeat hospitalizations and access to information available in inpatient medical records. Hospitalists have the opportunity to use the services of many ancillary providers within the hospital system. For example, hospitalists caring for children may have access to information about social services and community resources not readily available to the PCP. Communication between the PCP and hospitalist prevents unnecessary duplication of diagnostic tests and facilitates consultation and a smooth transition between outpatient and inpatient care.

Successful interaction among different physicians and other professionals promotes an atmosphere of collegiality and mutual learning, and creates an open and supportive professional and educational medical community. Communication fosters a culture of safety and may reduce medication errors and unnecessary medication use. It supports patient education, has the potential to improve the use of chronic and preventive medicines, addresses the needs of patients with limited resources or without an MH, helps coordinate the care of chronically ill and vulnerable patients, and provides greater insight in family conferences.

Box 10-1 provides guidance for communication between PCPs and hospitalists. A partnership in patient and family education may help prevent unnecessary hospitalizations and may promote patient and family knowledge about chronic diseases, medications, and disease triggers. Many concerns regarding patient safety, such as medication reconciliation, follow-up of outstanding laboratory results, or the need for additional outpatient clinical tests or procedures, can be addressed by establishing effective and collegial communication among physicians. Both the PCP and the hospitalist are advocates for the patient. Differences in approach to diagnosis and treatment should be discussed in an open and mutually respectful manner. An optimal plan is a collaborative one; however, ultimately, the attending physician of record, the hospitalist, will be responsible for making decisions about the hospital stay. Any differences should be settled before discussion with the family. Involving the patient and family in these care decisions is an important and necessary part of the care collaboration. Effective communication and handoff also increases physicians' efficiency and satisfaction in their own practices.

Transitions in patient care when a hospitalist assumes the care of a PCP's patient and vice versa, such as inpatient hospitalization and discharge, carry the risk of losing patient information and decreasing communication. Similarly, subspecialty consultations, procedures, and therapeutic suggestions can be lost to the PCP if not adequately communicated by the hospitalist. Thus, in addition to collegial communication, continuing education for hospitalists, subspecialists, and PCPs in physician–physician communication and physician–patient communication improves rapport, a necessary component of the therapeutic relationship between the members of this triad.

Methods of communication are varied and often tailored to a particular service and patient population, although most PCPs prefer to communicate with hospitalists by telephone at admission and discharge. Other options include faxes, transcribed dictation, and e-mail. It would be optimal to agree on a method of communication prior to or during the hospitalization, but this may not be practical, so a standard method of communication for that hospital program should be known and adhered to.

BOX 10-1 Guidance for Communication Between Primary Care Physicians, Hospitalists, and Families

- Communication should, above all, promote quality of care and patient safety.
- Communication between the hospitalist and primary care physician (PCP) should always occur at the time of admission, at discharge or transfer to a different institution, and during the hospitalization at the time of significant events and procedures (depending on physician preferences).
- During hospitalization, the child's family should participate in major decisions such as those regarding major procedures, transfers to other institutions, and changes in level of care. Family-centered hospital rounds are an effective method of encouraging this communication.
- Hospitalists, PCPs, and subspecialists should be easily accessible to each other by a mutually agreed upon method of communication or based on the model for that institution, be it by phone, e-mail, sharing electronic medical record notes, or another method.
- PCPs should maintain communication with patients and their families who are on a hospitalist service and are encouraged to visit the child in the hospital, especially a child with a chronic condition or special health care needs. The PCP should discuss any medical advice with the hospital team before discussion with the family.
- The treatment plan and follow-up suggestions are an essential part of the communication about transfer of care at discharge. The patient and family should participate in the generation of the health care plan, have ownership of it, and document their understanding of it. The use of care coordinators can be extremely helpful in that process.
- Hospitalists, subspecialists, PCPs, and families share in the responsibility to ensure adequate follow-up after discharge, including establishing follow-up appointments, informing patients of outstanding clinical test results, and educating patients about the necessity for follow-up care.

Derived from Eichner JM, Cooley WC. Coordinating the medical home with hospitalist care. *Hosp Pediatr.* 2012;2(2):105–108.

TRANSITION OF CARE AT DISCHARGE

Interventions that increase patient satisfaction and improve safety after discharge are essential for hospitalist services. These interventions may include identifying a specific individual from the hospitalist team (a care coordinator) to contact patients after discharge, identify patients who have missed follow-up appointments, and track pending clinical results. For some services, providing follow-up telephone calls from a pharmacist has helped answer questions and resolve medication-related problems. First and foremost, communication should promote patient safety. The treatment plan must include preparations for follow-up after discharge and a method of communicating outstanding test results.

The importance of a controlled transfer of patient information after discharge cannot be overemphasized. The hospitalist and the PCP share responsibility and liability for patient care. A practice that focuses first on the best interests of the patient will ultimately benefit the physicians involved and help improve the quality of care after discharge from the hospital. The physician's legal duty to provide follow-up care is well established. In the case of hospitalists and PCPs, this responsibility is shared. The patient and family must leave the hospital with the following necessary tools: an understanding of the diagnosis and inpatient treatment, what tests results are still pending, a recognition of the need for any ongoing medical therapy or routine follow-up care, and a follow-up care plan with an identified PCP who has timely, adequate, and accurate information about the hospitalization, including any pending laboratory or other clinical test results. There also should be a clear understanding by the patient and family, hospitalist, and PCP regarding who should be contacted and by what method during that critical period between discharge and the follow-up appointment. This can be provided by a care coordinator as part of the hospital team.

The failure to relay information about clinical test results that are outstanding at the time of discharge is a problem documented in the medical literature and identifies an important patient safety issue. By definition, hospitalist services have a large volume of potentially actionable test results pending at the time of discharge and may not have an established system for tracking these results or providing follow-up information to PCPs or patients. Fortunately, an inherent strength of hospitalist services is their ready access to patient information through integrated hospital information systems and their ability to coordinate care for patients with other specialists. These systems need to be used to enable and promote collaboration and communication between hospitalists and community physicians. Thus, there needs to be a system in place to ensure prompt, reliable, and confidential transfer of patient information between the hospital and PCP's medical record systems.

CONCLUSION

The presence of a skilled pediatric hospitalist on an inpatient service provides a unique opportunity for teaching many members of the medical team. It is an ideal arrangement for direct evidence-based clinical teaching of medical students and residents, as well as providing immediate interaction with nursing staff and other ancillary staff. There are many benefits to including the family in these efforts. A pediatric hospitalist presence in the hospital promotes the consideration of pediatric concerns at many levels and

provides a pediatric focus during administrative and peer-review hospital committee activities. In addition, the pediatric hospitalist has the opportunity to improve the quality of care provided to hospitalized children by implementing and overseeing the use of evidence-based diagnosis and treatment guidelines published by the American Academy of Pediatrics and other professional organizations. They may also conduct other quality improvement activities, such as reducing nosocomial infections and adverse reactions to medications.

TOOLS FOR PRACTICE

Engaging Patient and Family

- *Building Your Care Notebook* (Web page), American Academy of Pediatrics (medicalhomeinfo.aap.org/tools-resources/Pages/For-Families.aspx)
- *Emergency Information Form for Children with Special Needs* (template), American Academy of Pediatrics (www.aap.org/advocacy/blankform.pdf)
- *Hospital Stay Tracking Form* (file archive), National Center for Medical Home Implementation (medicalhomeinfo.aap.org/tools-resources/Documents/Hospital%20Stay%20Tracking%20Forms.zip)
- *Pediatric Care Plan* (template), American Academy of Pediatrics (medicalhomes.aap.org/Documents/PediatricCarePlan.pdf)

Practice Management and Care Coordination

- *Coding for Medical Home Visits* (fact sheet), American Academy of Pediatrics (www.aap.org/en-us/professional-resources/practice-support/Coding-at-the-AAP/Pages/Coding-for-Medical-Home-Visits.aspx)

AAP POLICY

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Chapter 11

ETHICAL AND LEGAL ISSUES FOR THE PRIMARY CARE PHYSICIAN

Lainie Friedman Ross, MD, PhD; John D. Lantos, MD

The hallmark of clinical ethics in the setting of general internal medicine is its focus on the competent adult patient. In the physician–patient dyad, the patient is the decision maker, and the focus is patient autonomy. If the patient becomes incompetent, the focus remains on patient autonomy because the surrogate is supposed to be guided by the principle of substituted judgment; that is, to make decisions based on what the patient would have chosen if able to do so. In contrast, the foundation of pediatric clinical ethics is a triad that includes the physician, the child, and his or her parent or parents or guardians. In the triad, the legally entitled decision maker is not the patient. Historically, parents were legally empowered to make virtually all decisions for their children. All children were presumed to be incompetent, and their opinions were not sought. The guiding principle was the *best interest of the child* standard. However, in the past 2 decades, sociopolitical developments around the world have increased the child's legal authority and given the child, particularly the older child, his or her own voice (autonomy). Some people argue that mature children (specifically adolescents) should be allowed to make their own decisions without their parents' permission, even without their parents' awareness. This issue is an area of tension and controversy because reasonable people disagree about the degree to which children's values and choices should direct their health care.

Much of the literature of pediatric ethics focuses on the extreme cases: the premature infant who weighs 600 g, the child who has leukemia whose parents refuse chemotherapy, or the child whose sibling needs a kidney transplant. The unique issues that pediatricians in primary care practice face have not received comparable adequate scholarly attention or rigorous analysis. This circumstance may be because the ethical issues that arise in the daily practice of primary care pediatrics are usually not concerned with decisions about illnesses that are immediately life threatening. Nevertheless, pediatricians in primary care practice often face decisions that may have profound effects on a child's physical and mental health and on many emotional, spiritual, and economic elements of family life.

Societal standards about difficult moral choices in medicine have evolved through a dialogue among patients, patient advocacy groups, pediatricians and other physicians, bioethicists, professional societies, and the various branches of government. Legal disputes have been especially important for issues such as do-not-resuscitate orders, brain death, and treatment withdrawal. The controversies and disputes that arise in primary care seldom lead to legal actions. When they do, lower courts, rather than appeals courts, often decide these disputes. Lower-court

decisions are seldom published and do not establish precedent. As a result, in many cases, neither statutory law nor case law is directly applicable to the issues at hand.

This chapter presents common scenarios that arise in primary care pediatrics and that raise thorny ethical issues. Some of these issues are procedural—that is, they require a decision about who should decide. Others are substantive—that is, they require consideration of what the right decision is and what constraints should apply to any decision maker. In some cases, legal constraints exist on decision making; in others, the law allows the physician wide latitude. The focus is on situations in which the law is less clear because many applicable laws vary from state to state and because these situations require that pediatricians make their own moral judgments.

CASE STUDIES AND ANALYSIS

Case 1

Alan, an 8-year-old boy, comes to your office because he has multiple warts on his hands. The school is concerned that he is contagious, and he is not allowed to participate in contact sports until his condition is treated or, at a minimum, is under treatment. You explain to Ms A, his mother, and to Alan that many therapeutic options are available, including cryotherapy in the physician's office, a salicylate-based therapy or duct tape that is to be applied nightly, and watchful waiting. Ms A requests that you give Alan the in-office treatment. Alan says that he does not want any painful treatment and will apply the ointment nightly. What do you do?

Discussion

On the surface, the case does not appear to involve an ethical issue because Alan, his mother, and the pediatrician all agree that Alan needs treatment. However, many very different treatments are available. Each approach has different benefits and burdens, and the evidence for the superiority of any one treatment is not strong. The child prefers one balance of the benefits and burdens, and the parent prefers another. Their different values, when brought to play on the therapeutic options, have created a conflict between the parent and child. The pediatrician may not have a strong opinion about which option is best.

The first step in any such conflict is further discussion. Understanding why Ms A prefers the liquid nitrogen therapy would be valuable. Issues to be weighed include efficacy, cost, convenience, attendant risks, and compliance. Ms A's choice is pragmatic; she sees the liquid nitrogen as being more reliable than other treatments. Ms A is afraid, based on experience, that her child will be poorly compliant with the nightly salicylate-based treatment. She does not want to have a nightly battle. Alan has had liquid nitrogen therapy before and finds it quite painful. He promises his mother that he will comply with the nightly ointment applications.

In many such discussions, parents and children will come to an acceptable compromise. For example, Ms A may agree to a trial of home therapy during which Alan will agree to apply salicylate without parental reminders at home. If he fails to do so, then they will return for cryotherapy. In some cases, however, their positions are intractable, and the question remains, "Who should have the final word?" The American Academy of Pediatrics (AAP) Committee on Bioethics published recommendations regarding the roles of parents and children in decision-making for children. The committee recommends that the resolution of conflicts between parents and children depends, in part, on the child's decision-making capacity. For the child whose decision-making capacity is developed, the committee recommends that the child's decision be final. For the child whose capacity is developing, such as Alan, the committee urges the physician to try to achieve consensus. If the child and parent cannot reach consensus, then the AAP supports third-party intervention. Although some people may find this approach reasonable, others might find it hopelessly cumbersome. What third party would be available in a busy pediatric office? Furthermore, some parents may be intolerant of third-party scrutiny. These parents may find even the physician's scrutiny an inappropriate threat to their legitimate parental authority.

What are the pediatrician's options if consensus is not achieved? If the pediatrician sides with the parent, then the protesting child will receive a painful treatment. What if the child resists? Such actions convey to children the problematic message that their opinions do not matter. On the other hand, to side with children on the grounds of developing maturity places parents in an awkward position because they must now buy the medication and apply it to their child's hands nightly. What if Ms A resists and says, "OK, doctor, at what time will you come by to place the medicine on Alan's hands?" Her response demonstrates the bind that physicians have in their relationships with their patients. The challenge for professionals is to be caring without taking unnecessary control of the life of the child for whom they do not and cannot take full responsibility.

In a case such as this one, it appears reasonable that parents should have ultimate decision-making authority. The risks of either treatment are low, as are the burdens of therapy, and the child is at an age at which it is unlikely that he would be capable of taking responsibility for his own medication regimen. Still, physicians have the right, and the obligation, to involve children in the decision-making process and to explain to them why their wishes and requests are being overridden, even if their parents complain that this action threatens their autonomy and authority.

Case 2

Betty, a 15-year-old girl, comes into the physician's office for a yearly physical. Her examination is normal. She attends St. Mary's High School, where she is on the honor roll. She is popular with her friends and tells you that she has recently fallen in love with Bob. She says that she is not sexually active yet, but she asks for birth control pills. She also asks that you not tell her parents because she knows that her sexual activity is

against their moral and religious beliefs, and she fears they will prohibit her from seeing Bob.

Case 3

Vicky, a 15-year-old girl, is brought to your office by her mother, Ms V, who states that she knows that her daughter is sexually active, and she wants her to get long-term contraception to avoid pregnancy. Ms V is a single mother who became pregnant with Vicky when she was 14, and she wants to protect her daughter from the hardships she faced. Vicky acknowledges that she has a boyfriend, Tom, and is sexually active. She states that he wants her to get pregnant, although she is ambivalent. She does not want contraception because she fears her boyfriend will leave her.

Discussion

Current data indicate that more than 51% of high school girls and 61% of high school boys have had sexual intercourse. Almost 850,000 American adolescents become pregnant every year. Many teens do not seek medical or gynecologic care or contraception for months or even years after they initiate sexual activity. Most teens who become pregnant are unmarried, and most of their pregnancies are unplanned. More than 60% of these girls will decide to take the pregnancy to term, and virtually all of these teenagers will take on the responsibilities of parenthood. Pregnant adolescents and their fetuses have a higher incidence of medical complications than older women. Their children do not fare as well psychosocially as do children of adult mothers. Thus, one can say both that Betty is acting unusually responsibly for a 15-year-old and that Ms V's concerns are well founded.

Both these requests should be interpreted as an opportunity for dialogue. The first step may be to assess the voluntariness of Betty and Vicky's sexual (or potential) sexual activity. The pediatrician should ascertain whether Bob and Tom are classmates and of similar age, or whether they are much older than Betty and Vicky, with the latter possibility raising concerns of sexual predators. Even if they are of similar age, different states have different laws about when minors can legally consent to sexual activity and different laws regarding abuse, statutory rape, and state reporting requirements. Assuming that the pediatrician is convinced that Betty and Vicky are not in abusive or nonvoluntary relationships, the pediatrician should discuss with each teenager the consequences of her decision. Betty should be commended for seeking to be sexually responsible, but she must also be made aware of the risks of sexual activity, the efficacy of the various methods of contraception, and the fact that abstinence is the only 100% effective way to avoid pregnancy. The pediatrician should discuss with Betty what she might do if she were to get pregnant even though she has been taking the pill. Other questions that the pediatrician should ask are whether Betty has discussed with Bob what they would do if she were to get pregnant, and how her deception will affect her relationship with her family. Vicky's physician may want to address the issue of whether Vicky finds this three-way conversation embarrassing, perhaps suggesting to Ms V that the best way to protect Vicky from an unwanted pregnancy might be to encourage her to talk with the pediatrician confidentially. Ms V and Vicky may be receptive to this idea. This approach does not resolve whether Vicky should receive the treatment that her mother requests but that Vicky rejects. However, it may give the pediatrician an opportunity to discuss with Vicky the most likely outcome of adolescent pregnancy: single parenthood and its attendant responsibilities. The pediatrician may try to help her see that pregnancy should be a positive decision (ie, I want to be a parent) and not a passive decision (ie, it will make my partner happy). The pediatrician may want to encourage Vicky to get counseling to help her sort out the complicated issues that she is facing.

Although parents generally have the legal right and responsibility to make medical decisions for their adolescent children, treatment related to reproductive health is an exception under the special consent statutes. These statutes vary by state and in their scope, and may apply differently to physicians in different practice settings, but they all give adolescents the legal autonomy to seek and consent to the diagnosis and treatment of drug and alcohol abuse, contraceptive counseling, and the procurement of contraceptives.

Some states even allow minors to consent to abortions without disclosure or consent from their parents. The statutes were designed to encourage adolescents to seek health care for problems they might deny or ignore or for which they might delay seeking treatment if they had to get parental permission. Pediatricians should know the specifics of laws in their state. Although such statutes allow physicians to provide this care, they do not compel them to do so. Thus, a pediatrician facing a patient such as Betty has the legal latitude to make a moral decision. However, even a pediatrician who thinks that prescribing contraception is inappropriate for Betty should inform her that she has a right to obtain contraception and should refer her to another provider.

The purported purpose of the specialized consent statutes is laudable: to encourage early, responsible sexual health care for adolescents. The pragmatic justification is compelling: Given that adolescents can be and frequently are sexually active even when birth control and other sexual health services are relatively inaccessible, they should be given the opportunity to be responsible for their sexual activity. However, whether the pragmatic justification is sufficient to justify empowering all adolescents to consent to or refuse all types of reproductive health care is unclear. Rather, both moral and pragmatic considerations might lead one to empower Betty and to disempower Vicky. In both cases, the goal would be to minimize the chances that either girl would get pregnant.

Three moral arguments can be made in these situations that would lead to 3 different decisions. First, we might base these decisions on a pure best-interest standard. That is, we might simply judge that it is not in either Betty or Vicky's best interest to get pregnant. Thus, we would make the decision that best advances these interests and prescribe contraceptives for both. This decision can be framed as a way of preserving their future autonomy; that is, granting autonomy to adolescents regarding their sexual activity when they

are 15 may be autonomy-restricting over a lifetime. As with many decisions that children make, we might justify restricting a child's autonomy now to give her greater lifetime autonomy. Second, one might argue that these teens have the right to make decisions for themselves in these matters. Following this view, we would confidentially prescribe contraceptives for Betty but not for Vicky. Third, one might argue that parents have a valid third-party interest in their children's development and activities, even when the children become teens and achieve a significant level of competency. To act on these interests and to participate in their children's moral development, they need to have the opportunity to try to inculcate their beliefs through rational discourse. They can accomplish this task only if they are aware of what their teens are doing. This argument acknowledges the child's decisional capacity, but it also asserts that decision-making capacity is necessary but may not be sufficient to grant an adolescent health care autonomy. In this case, one might prescribe contraception as requested by Vicky's mother but not for Betty, whose parents are not aware of their daughter's intentions.

This range of responses is consistent with both the specialized consent statutes and the AAP position on consent, permission, and assent. Teens are empowered to obtain contraception, but pediatricians are not required to provide such treatment. Parents are empowered to request medical treatment that they deem to be beneficial to their child, but pediatricians are not required to provide it. Thus, pediatricians must make a personal moral decision about how they will respond with one major caveat: When a pediatrician is not willing to provide a treatment that is a valid medical option (eg, contraception to minors), the pediatrician does have an obligation to refer the patient and family to another physician who is willing to do so.

Case 4

Ms C calls you the day before she is scheduled to bring in her 14-year-old son Charles for his yearly physical examination. She tells you that Charles was previously an A student but now is getting Cs and Ds. The family is going through turmoil because Mr C moved out of the house 3 months ago to live with his pregnant girlfriend. Ms C admits to being depressed and cries easily but has not sought outside help. Charles has been withdrawn and often comes home late and refuses to tell his mother where he has been. She fears that Charles is using drugs and would like you to screen him without telling him what you are doing.

Discussion

Ms C's request is a call for help. Ms C and Charles need counseling regardless of whether Charles is using drugs. Ideally, both of his parents need to realize how their actions and emotions are affecting their son's behavior. Charles needs parental supervision at a time when both parents are disengaged for different reasons. Each year, more than 1 million children experience the divorce of their parents. The parental conflict that is associated with the separation is often expressed as behavioral problems in the child, and the pediatrician should be prepared to provide support or to refer for appropriate counseling.

A crucial question for Ms C is, "How will the surreptitious drug testing help?" A test that comes back negative does not prove that Charles is not using drugs. False-negative tests can occur because the half-life of many drugs is less than 24 hours and because urine drug testing applies to only some of the substances more commonly abused. Serum testing is more sensitive but can only be used for specific drugs, so you would need a list of the drugs that are suspected. If the test is positive, it indicates recent use but is not diagnostic of substance abuse. If the screen comes back positive, then Ms C will need to decide how she will approach Charles. Charles is presently not trusting of adults who have betrayed him. Surreptitious testing will increase his distrust.

The preferable course of action would be to ask Ms C to give you permission to establish a confidential relationship with Charles. You might explain that this approach is likely to be much better for Charles in the long run. Most parents will likely be willing to accept this advice. If Ms C gives you such permission, then you should arrange to meet with Charles privately and explain the confidential nature of the relationship. You should be honest about when confidentiality would be broken–specifically, in cases in which you believe that Charles is a danger to himself or others.

The opportunity to speak confidentially to his physician may be what Charles needs to help him cope with the turmoil at home. Charles may be willing to discuss whether he is abusing drugs and may be willing to be tested for drugs as well. However, many other issues need to be addressed with Charles that are even more compelling. Is he suicidal? Is he engaging in any other risky behaviors (of which drug use is but one dimension)? Is he depressed? Is he willing to seek counseling or begin antidepressant medication, if recommended? Are there any adults whom he trusts?

Despite your suggestion, Ms C may still demand that you test Charles for drugs. In fact, situations occur in which the grounds for suspecting drug abuse are compelling, and teens who are using drugs may not be in a position to assess the risks and benefits of testing or treatment. Pragmatically, however, testing Charles would be difficult without his cooperation unless he was deceived about the purpose of specimen collection. Pediatricians (similar to other physicians) should not deceive their patients. Thus, if Charles's mother insists on testing, then the pediatrician should insist on informing Charles of the nature of the test. Ideally, Charles should voluntarily agree to testing. In fact, some states prohibit testing a minor for drugs without the minor's consent. There are exceptions for urgent and emergent care, but they would not apply in the case presented. Even where legally permissible, involuntary testing should be performed only if reason exists to doubt his competency or if information exists that strongly suggests Charles is at high risk for imminent danger from his substance abuse. Even if testing is not voluntary, the disclosure that testing

will be performed will help maintain trust and keep the door open for future communication. Ms C has a moral obligation to care for her son and to determine what medical information she needs to do so. However, this obligation does not give her the right to demand that you lie to him about what you are doing or to violate his right to privacy without compelling evidence that it is in his medical best interest.

The physician also should use this appointment and the discussion about drug testing as an opportunity to encourage Charles and Ms C to seek counseling and to give Charles anticipatory guidance about any and all risky behaviors in which he is involved. Pediatricians should be aware that in recent years, a number of companies have begun to market home drug-testing products directly to parents. If Ms C cannot get you to test Charles, she may test him at home without having full capacity to interpret the results. As such, it behooves the pediatrician to work with Ms C to get her to agree with the plan of action.

Case 5

Mr and Mrs D are the proud parents of David, a well-appearing 6-week-old boy. During their first well-baby visit, you learn that Mr D had retinoblastoma as a child and had his left eye removed. You recommend genetic testing to determine whether the child is at risk. Mrs D states that they were offered such testing in utero and that they refused and still refuse genetic testing.

Discussion

Retinoblastoma may be inherited as an autosomal dominant gene, or it may develop spontaneously. Given that Mr D had retinoblastoma, David has a 50% risk for developing retinoblastoma. Before the discovery of the gene for retinoblastoma, children born into families that had a positive history for retinoblastoma underwent ophthalmologic surveillance every 3 months. The value of the genetic information is that if David tests negative for the gene, then he can avoid frequent eye examinations. If he tests positive, then he will need to undergo frequent screening to enhance the likelihood of early detection. If detected early, then the prognosis for survival and vision is improved.

Testing young children for early-onset conditions encompasses 2 very different categories: conditions such as Duchenne muscular dystrophy, for which early (presymptomatic) diagnosis and treatment do not affect the course of the disease; and conditions such as retinoblastoma, for which early diagnosis and treatment may improve treatment or even save lives.

In the first category of early-onset conditions, the value of presymptomatic diagnosis is to help avoid delay in diagnosis when early symptoms are nonspecific, to target surveillance screening more accurately, to allow parents to prepare for a child who will have special needs, and to give parents information to use in their reproductive planning. On the other hand, early diagnosis may be detrimental in a number of ways. The *vulnerable child syndrome* has been shown to cause morbidity that may be even greater than that associated with the disease that is diagnosed. Early diagnosis may affect parent–child bonding adversely if the parents hold back on emotional investment because they fear their child will die. In older children, it may adversely affect the child's self-image and self-esteem. Finally, in the United States, obtaining appropriate health insurance for the child and even for healthy siblings was complicated by insurance discrimination against families in which a preexisting condition was documented. However, the passage and implementation of the Genetic Information Nondiscrimination Act (GINA) in 2008 ought to make such concerns obsolete. Parental expectations for the future may also be limited unnecessarily. For conditions in the first category in which early testing has not been shown to improve morbidity or mortality, the risk–benefit balance of presymptomatic testing will depend on the values and needs of each family. In such situations, parental choices should be respected. For conditions in the second category for which clear evidence exists that early testing might reduce morbidity and mortality, parental discretion may be limited by medical neglect statutes. In these cases, a pediatrician might choose to report a case to child protective services. Then, a judge would decide whether to order testing.

The value of presymptomatic testing in the second category is to prevent serious morbidity and mortality. Because articulating a compelling argument to explain why children should not be tested in these circumstances is difficult, wide consensus exists that children in families known to carry such genes should be tested. Also assumed is that parents are the child's appropriate decision makers. The question is whether, if parents refuse testing or diagnostic workups, physicians should feel compelled to seek state permission to override their refusal.

In such a case, the pediatrician needs to engage Mr and Mrs D in dialogue to try to determine why they are refusing testing. They may have refused genetic testing in utero because amniocentesis entails risks for morbidity and mortality and, assuming that a positive test would not have led them to terminate the pregnancy, would not have offered any tangible benefits. However, genetic testing for the gene for retinoblastoma in a 6-week-old child is a simple blood test, and the result clarifies whether the child needs frequent ophthalmologic follow-up. Mr and Mrs D may continue to refuse testing because of lack of knowledge, fear of stigma or discrimination, or fear that this procedure may interfere with obtaining insurance, particularly if either parent is looking for a new job, which may include a change in insurance.

What should be done if Mr and Mrs D continue to refuse testing? Ideally, knowing David's genetic status would be valuable, but as long as Mr and Mrs D are compliant with frequent surveillance, their decision is neither abusive nor neglectful. The eye examinations themselves are minimally invasive, although young children may require sedation. Physicians should respect this decision but realize that it adds the additional responsibility that they ensure that David does get appropriate quarterly examinations. If Mr and Mrs D refuse or fail to comply with quarterly ophthalmologic

examinations, then this failure is neglectful, and they should be reported to the appropriate child protection authorities.

Case 6

Ms F delivered Frances, a healthy full-term infant, 24 hours ago. Ms F is a very well-informed parent, and she requests that Frances not receive either vitamin K or hepatitis B vaccine because she does not want to put Frances through any more discomfort than the birth process. You come to draw the newborn screen for phenylketonuria and other metabolic conditions before discharge, but she refuses. She agrees to reconsider and will take the card to her private pediatrician, whom she plans to see in 2 days. You suspect that she will again refuse newborn metabolic screening. How should you respond?

Discussion

Traditionally, the conditions screened for with the Guthrie card were rare diseases for which early treatment would reduce morbidity and mortality. In 1968, the World Health Organization enumerated 10 criteria for evaluating screening programs, including that the disease must represent an important health problem for which an accepted treatment exists that can prevent most or all of the morbidity or mortality associated with the condition; that the screening test be simple and inexpensive and the follow-up confirmatory testing highly accurate; that a system be in place to ensure quick communication of results to relevant parties; and that the cost of case finding, diagnosis, and treatment be economically balanced in relation to expenditures on medical care as a whole. More recently, newborn screening programs are expanding, in part as a result of the development of tandem mass spectrometry and advances in gene chip technology, which allow for the detection of numerous conditions, not all of which meet all of the World Health Organization criteria.

Historically, there was wide variability in the number of conditions included in newborn screening panels. In 2005, the American College of Medical Genetics and Genomics (ACMG) and the Human Resources and Services Administration (HRSA) recommended a uniform panel including 29 primary and 25 secondary targets. This panel was endorsed by the Secretary Advisory Committee on Heritable Disorders in Newborns and Children. Today all states in the United States offer the uniform panel and some offer additional conditions as well. In the United States, 48 of the 50 states have mandatory universal newborn screening programs. Although screening is characterized as *mandatory,* in actual practice, parents can and occasionally do refuse testing. However, they generally are not asked for permission, and therefore, to refuse, they must be informed and proactive. Most parents (and physicians) are unaware of the parents' right to refuse.

Mandated medical interventions, whether diagnostic or therapeutic, override important parental rights. Generally, the state should not interfere in the medical decisions that parents make for their children. To do so undermines the family unit. The only exceptions to this rule are situations in which parental decisions expose the child to serious morbidity or mortality, although wide interpretation may exist as to what degree of urgency, likelihood of harm, or magnitude of harm may justify overriding parental rights. Thus, parents whose religious beliefs lead them to oppose blood transfusions should not be permitted to refuse blood for their child in a life-threatening situation. They may, however, refuse in situations that are less directly life threatening. Newborn screening does not meet the criteria of an imminent risk for immediate danger because the probability of harm is remote. Each of the conditions included in the newborn screen occurs in fewer than 1 in 1,000 children. Some of these conditions may be diagnosable clinically; some may never manifest clinically. A parent who refuses newborn screening is taking a very small, albeit serious, risk. Their refusal should be respected.

Nevertheless, physicians should educate parents who refuse screening so that they understand why physicians believe that the benefits greatly outweigh the risks. Most parents will then accede to screening. In Maryland, where testing is voluntary, fewer than 1 parent in 1,000 refuses testing for newborns which is less than the number of children not tested because of lost and improperly obtained specimens.

Given the experience in Maryland, one might ask whether parental permission should be required for newborn screening. The arguments for seeking parental consent for newborn screening are twofold. First, procuring parental permission for newborn screening is a symbol of respect for the family—respect that is well placed, given that families are the primary source of childrearing and given that families, and not the state, will bear the greatest costs if diagnosis is delayed. Second, by requiring consent, parents must be educated about the purpose and limitations of screening, which may give them incentive to follow up on abnormal screening results. Knowledge of negative test results can be reassuring to parents, particularly those who have personal knowledge of any of the conditions for which their infant is being tested.

The major benefit of not requiring consent is to simplify the process of screening. Obtaining parental permission for newborn screening can be time-consuming. In this day and age, physicians are more and more pressed for time. In some cases, they may not have time to seek parental consent, and newborns may suffer as a result. A related argument is that the consent process for newborn screening is perfunctory. Neither argument morally justifies circumventing the consent process, although the practicalities may make true informed consent impossible. If each condition would only require a minute of explanation, consent might take more than an hour with expanded screening panels. Given the public health value of many of the conditions screened for, the goal of the consent process for newborn screening should not be to fully inform parents of each condition, but rather to inform parents of the general purpose of population health screening, which is to find individuals at risk for conditions for which early intervention reduces morbidity and mortality. For most parents, this explanation will be adequate. For parents who want additional information, pamphlets should be available, and referrals for more extensive counseling should be possible. In rare cases, parents will choose to opt out.

Given the low probability of a positive test, these parents should be counseled, but their refusals should be respected unless prohibited by state law (eg, Nebraska).

Case 7

Tina is a 4-year-old new patient. Her parents are seeking to enroll her in school for the first time. You ask for Tina's immunization records, and her parents state that she has received no immunizations. They request that you write a school note excusing their daughter from vaccination based on religious beliefs. On further questioning, you discover that the parents do not really have a religious objection to immunizations but have refused immunizations because they have heard that these vaccines may cause seizures or autism.

Discussion

Childhood immunization rates are among the 10 leading health indicators used to assess the health of the nation as part of the *Healthy People 2010* initiative, reflecting the high value placed on childhood immunizations. In the United States, childhood vaccinations for numerous infectious diseases are mandatory for entry into public schools and licensed child care facilities, although some private religious schools do not require them. Despite the success, the mandatory nature of immunizations represents a tension between individual autonomy and public health. Most states recognize a religious or philosophical exemption, although the courts have found that evaluating the sincerity, strength, and religious or philosophical nature of the refusals can be legitimate.

Parents refuse vaccinations for many reasons. For some parents, refusal is based on religious or philosophical beliefs; for others, it is based on fear of vaccine safety. In the 1970s, a report in *Archives of Disease of Childhood* suggested a connection between the whole-cell pertussis vaccine and neurologic damage in children. This finding was a major impetus to developing a safer acellular pertussis vaccine. In the late 1990s, fears arose over the measles-mumps-rubella (MMR) vaccine and its relationship to autism after the *Lancet* published a report of severe developmental regression in children by Wakefield and colleagues. The research team noted that the onset of symptoms occurred after MMR immunization, although they had not proved a causal link. In 2003, Simon Murch, one of Wakefield's collaborators, denounced assertions of a link between MMR and autism and declared the existence of "unequivocal evidence that MMR is not a risk factor for autism." In 2004, evidence revealed that Wakefield had concealed the fact that his research had been funded in part by the legal team seeking redress for parents who believed that their children had been injured by the MMR vaccine, and many of the original collaborators retracted their support for a link between autism and the MMR vaccine. However, it was not until 2010 that the *Lancet* fully retracted the manuscript, 1 week after the General Medical Council (UK) found Wakefield guilty of dishonesty and flouting ethics protocols. In addition, numerous medical studies, including a large Institute of Medicine review, have confirmed the lack of association between autism and the MMR vaccine.

In the United States, children who are undervaccinated are demographically different from children who receive no vaccinations. Risk factors for being underimmunized include minority status, poverty, living in an urban area, living in a household with more than 3 children, and low maternal education. In contrast, children who have no vaccinations tend to be white children whose parents are married, older, and wealthier or children in religious communities whose parents have a religious objection to immunization. They often live in communities of like-minded families. The clustering of these families decreases herd immunity and makes these communities more susceptible to outbreaks. In September 2005, 4 children in an Amish community in Minnesota were found to have polio, a disease that had not been seen in the United States since 1979.

What should a pediatrician do when parents refuse recommended immunizations? Some pediatricians will discontinue care for such families. They claim that they cannot care for patients who do not trust their medical recommendations. In contrast to this approach, the AAP Committee on Bioethics recommends that the pediatrician should listen carefully and respectfully to the parents' concerns and to share honestly what is known about the risks and benefits of the vaccine in question and to correct any misconceptions and misinformation. They should explore the possibility that cost is a reason for refusal. Rather than dismiss the family, the AAP recommends that pediatricians take advantage of their ongoing relationship with the family and revisit the immunization discussion on subsequent visits. The AAP has also developed a form to document the parents' refusal.

If parents refuse immunizations for their children, then the pediatrician should document this refusal on the school form. In some states, this documentation is adequate for school entrance. In other states, parents may have to provide additional evidence as to the philosophical or religious nature of their objection.

Case 8

Mr and Ms G come to the clinic with Gary, their 5-year-old son. Gary was adopted as a newborn. Mr and Ms G have told you they plan to tell Gary about his origins, but each time you ask, they give reasons why they have not yet done so. They have kept the adoption secret from all but their immediate family.

Case 9

Mr and Ms S bring their 5-year-old child, Sam, for a well-child visit. The family has just moved from California. As you try to take a full medical history, the parents become visibly uncomfortable. Finally, Mr S takes Sam out of the room to play in the waiting room, at which time Ms S explains that they had infertility problems and used donor sperm and that Mr S is not Sam's genetic father. They have only sketchy information about the sperm donor, who was a 25-year-old healthy white medical student. They have chosen not to tell Sam about his genetic parentage.

Discussion

Adoption is a legal procedure through which a permanent family is created for a child whose birth parents are unable, are unwilling, or are legally prohibited

from caring for their child. Adoption has existed throughout history, although the focus has changed. Historically, "adoption served the needs of adults . . . for the purpose of kinship, religion or the community," in contrast to our current focus on the needs and well-being of the child.

In the United States, formal adoptions peaked in 1970 when about 175,000 adoptions occurred. Adoptions have decreased because of many social factors, including the decrease in the stigma of single mothers and the increased availability of abortion. Since 1987, the number of adoptions annually has remained relatively constant, ranging from 118,000 to 127,000. Despite the large number of children and families who are directly affected by adoption, the medical literature on adoption is scant.

Before World War II, professional adoption workers advised, if not insisted, that children be told of their adopted status for the pragmatic reason that learning of adoption from parents in a loving environment rather than by well-meaning or even malicious neighbors, schoolmates, or relatives was better for the child. After World War II, the professional community argued against disclosing. By the mid-1970s, the pendulum returned in favor not only of disclosing adoption but also of openness in all aspects of adoption. Nevertheless, some families still try to keep the adoption a secret.

Assisted reproductive technologies (ARTs) offer individuals another possible means to achieve parenthood (Chapter 81, Assisted Reproductive Technologies, Multiple Births, and Pregnancy Outcomes). ARTs have offered some new twists. Whereas adoption separated genetic and social parenthood, ARTs allow individuals to separate genetic, gestational, and social parenthood. For example, through in vitro fertilization, a woman can gestate a fetus who is the product of her husband's sperm and a genetically unrelated egg donor whose identity is often unknown. More common are children born by the use of sperm donors, such as in the case of Sam. In the early days of donor insemination, the husband's sperm was mixed with the donor's sperm to leave open the possibility that the child was the genetic heir. Now, determination of paternity is widely available and accessible and makes this pretense obsolete. Although there was a lot of secrecy surrounding gamete donation, there has been a movement to encourage disclosure of gamete donors. Recently, the American Society for Reproductive Medicine has issued a statement encouraging the disclosure of gamete donation, and this trend is even greater in some other countries where openness is required by legislation. In most of the empirical studies to date, nondisclosure is common, but some studies are showing greater disclosure.

For Gary and Sam, the clinical value of knowing their correct genetic family history is that it may allow their health care providers to perform particular diagnostic measures or to counsel them about ways to minimize their genetic susceptibilities through particular lifestyle choices. As our understanding of genetics improves, emphasis on collecting family history information increases, and yet data suggest it may be highly inaccurate. Family history is growing in importance because we understand that many illnesses have a genetic component; and yet, we are also learning that genotype frequently does not correlate with phenotype and that family history may or may not provide additional data.

Questions also arise as to whether children have a right to know their genetic inheritance, whether parents have a right to maintain secrecy, or both. The literature about the psychological risks of disclosure and nondisclosure is limited and inconclusive. Nevertheless, today most psychologists and psychiatrists support disclosure because of its role in health care screening, diagnosis, and treatment and the importance of genetic identity to one's self-identity. Reasons to respect nondisclosure include the potential threat that such knowledge may pose to the parent–child relationship and the integrity of the family. Which reasons are stronger depends on how one weighs the advantages and disadvantages.

Although it might be argued that knowing their biologic identity is better for children, the physician's right to interfere in interpersonal family dynamics is and should be limited to situations of clear-cut abuse or neglect; nondisclosure of biologic relationships does not rise to this level. Pediatricians should encourage disclosure in a developmentally appropriate manner and should discourage parents from *waiting until the right moment*. Parents can be referred to one study from the United Kingdom that queried adolescents and adults conceived through gamete donation and found that it was "less detrimental for children to be told about their donor conception at an early age." The physician should encourage disclosure on the grounds that (1) secrecy may be detrimental to a trusting relationship between parents and children; (2) later discovery by the child may have an adverse effect on self-esteem; and (3) the child otherwise may learn of the genetic discrepancy in a less secure setting (eg, accidentally overhearing a relative). Nevertheless, physicians should not disclose this information to children without the parents' permission.

Case 10

Ms H brings her 17-year-old son Harold to the clinic for a preparticipation high school basketball physical examination. On taking the history, you learn that Harold's father died from a heart condition last year at the age of 40 years. Harold's uncle died in his late 20s when playing competitive tennis. You are concerned about the possibility of a familial cause of sudden death caused by a cardiac condition known as hypertrophic obstructive cardiomyopathy (HCM). You recommend either an echocardiogram or genetic testing to see whether Harold has HCM. Harold and his mother refuse. You then write on his school physical form that he is at risk for HCM and should not participate in school sports without a cardiac workup. Harold and his mother are quite angry. Harold is an all-state player and is being recruited heavily by many universities. The mother plans to take Harold to another physician and demands that you not inform his school or anyone else of your concerns. Harold and his mother do not disclose the family history to a

colleague in a practice across town, who approves him for interscholastic athletics.

Discussion

HCM is an autosomal dominant condition that is usually asymptomatic in preadolescents. It is an idiopathic cause of cardiomyopathy, and the risk for sudden death, particularly during intense athletic activity, increases with age.

Harold is at risk for a life-threatening event that is exacerbated by physical activity. This diagnosis would make him ineligible for sports and take away his opportunity for a college sports scholarship. Of course, failure to diagnose this condition may result in premature death in a high school gymnasium. Competitive sports participation is clearly risky for Harold.

You try to convince Harold and his mother to have the echocardiogram. They acknowledge that he is at risk, but Harold states that basketball is his life, and he is willing to risk his life to play.

Harold and Ms H view the issue as one of autonomy. They understand the risks and benefits of playing, given Harold's possible cardiac condition, and they believe that playing basketball is better for Harold despite the risk for sudden death. They also view the issue as one of confidentiality. They ask that you not disclose to the school the family history that you discovered when interviewing Harold and his mother.

This case is one in which the parent and child are in consensus but in disagreement with the physician. The family's position for confidentiality and nondisclosure must be weighed against the physician's belief that he or she needs to protect this child from his mother and himself. Consensus guidelines state that adolescents with HCM should not participate in sports such as basketball. As a moral agent, the physician has an obligation to prevent a serious imminent risk for sudden death to a minor. Harold and his mother cannot relieve the physician of this obligation. The physician also has an obligation to protect the community. Imagine the reaction if Harold were allowed to play and he did die on the basketball court in front of many classmates and their families. Such an event might cause serious psychological trauma to the observers. How would the community respond if they knew that the physician might have prevented this event? The physician has an obligation to protect Harold and the community from such unnecessary trauma.

Harold's mother is correct that the physician must not breach confidentiality without the permission of the patient or parent. Instead, the physician should notify child protection about this unusual form of medical neglect, although whether child protective services would find the parent medically neglectful is not clear-cut given that the chance Harold has the gene is only 50%. They could require Harold to undergo testing if he wants to play sports. However, even if he has the gene, he is currently asymptomatic and his risk of having sudden cardiac death in the short term is low, but increases with age. Thus, the state will need to decide whether there is an imminent risk of death.

If the school were to be made aware (eg disclosure by child protective services), the school, in *loco parentis,* should prohibit Harold from playing basketball or other sports that may lead to his sudden death. This is true even after Harold turns 18 years of age.

Case 11

Mr K brings Kevin for his prekindergarten examination, during which you notice some linear ecchymoses on his back. You ask Kevin how he got them, and he answers that his father beat him for talking back at dinner last night. Kevin's father confirms this explanation, explaining that he believes that corporal punishment is effective. He admits to using a belt because his hand "did not produce the desired effect." You inform the family that corporal punishment that leaves marks is abusive and that you plan to report your suspicions of child abuse to the department of family services. The father is irate, arguing that discipline is a family matter and that his religious faith supports his convictions of *spare the rod and spoil the child*.

Discussion

An AAP policy statement on guidance for effective discipline begins by noting that "parents often ask pediatricians for advice about the provision of appropriate and effective discipline." The most controversial aspect of this issue is the role, if any, for corporal punishment. Although a recent survey of AAP members found that about 85% of respondents generally or completely opposed the use of corporal punishment, more than 90% of American families report having used spanking as a means of discipline at some time. And data show that children learn what they live: adults who reported corporal punishment as a child were more likely to use it with their own children. In contrast, corporal punishment is being abolished in many countries by statute on the basis that it violates the rights of the child.

Kevin's father raises the point that his actions are based on his religious beliefs. Some religious groups take a strong position in support of corporal punishment. Currently, religious exemptions to most of the child abuse and neglect statutes can be found, but the exemptions do not apply to corporal punishment, nor should they. The religious exemptions were written to protect parents who sought prayer-based therapy for their child rather than allopathic medical care; they were not meant to protect a parent from being charged with abuse for beating a child.

To examine the benefits and burdens of corporal punishment, the AAP cosponsored a consensus conference on this topic in February 1996. The conference concluded with 13 consensus statements that addressed the role of spanking and corporal punishment in parental discipline. Statement No. 6 comments on the lack of data on the effectiveness of spanking in general, and Statement No. 8 comments that the data show corporal punishment to be ineffective in older children and adolescents and "associated with increased risk for dysfunction and aggression later in life." The strongest statement against corporal punishment was Statement No. 12, which states that

"concerning forms of corporal punishment more severe than spanking, the data suggest that the risk for psychological or physical harm outweigh any potential benefits." More recent data show that even nonabusive corporal punishment is associated with increased aggressive behavior and delinquency in children.

Despite common use and acceptance of corporal punishment, the data show that, over time, spanking is a less effective strategy than noncorporal methods for reducing undesired behavior. Furthermore, this type of punishment becomes less effective with continued use. The AAP recommends that parents "be encouraged and assisted in developing methods other than spanking in response to undesired behavior." The AAP mentions both the *time-out* method and the removal of privileges as "two common discipline approaches that have been associated with reducing undesired behavior." The AAP statement noted further that many parents go beyond spanking and use an object or other forms of unacceptable corporal punishment: "When punishment fails, parents who rely on it tend to increase the intensity of its use rather than to change strategies." This action is no longer discipline but child abuse.

Pediatricians should help parents understand the facts about corporal punishment and to realize that any such punishment (beyond an occasional mild spanking) is unacceptable and will be reported. No morally justifiable reason exists for a parent to inflict physical harm on a child. Although physical manifestations of violence are an imperfect measure of the severity of punishment, they at least define an unacceptable threshold. The marks on Kevin are a sign that his father used more physical force than is morally acceptable. Reporting to child protective services may be necessary. The physician must work with this family to modify their discipline strategy.

Case 12

Mr and Mrs R call you to arrange a prenatal visit. They have a healthy 2-year-old daughter who was born by cesarean delivery weighing 8 pounds 5 ounces. The couple explains that they were very dissatisfied with their care because they had wanted a natural childbirth. They tell you that their nurse midwife "panicked" after 18 hours of labor and that they were forced into having an unwanted cesarean delivery. They have decided to have their second child at home with a lay midwife. They ask if you would be willing to be "on call" for the home birth, in case any complications arise. On further questioning, Mrs R is clearly well versed in the risks and benefits of vaginal birth after cesarean delivery (VBAC). She states that she lives within a 10-minute drive of a major hospital and will go there if things are "not going well." You argue that the additional time may risk her health and the health of the fetus. You tell her that VBAC is associated with uterine rupture and that this event might lead to death for both Mrs R and her baby. She says she understands but is determined to proceed with the home birth.

Discussion

In 2006, there were 38,568 out-of-hospital births in the United States, including 24,970 home births and 10,781 births occurring in a freestanding birthing center. A review article in 2010 noted that the benefits of home birth are fewer cesarean or operative vaginal deliveries, episiotomies, infections, and third- and fourth-degree lacerations. The major concern about home deliveries is that they may be associated with excess perinatal and neonatal mortality, particularly among nonanomalous term infants. The American College of Obstetricians and Gynecologists (ACOG) strongly opposes the practice. In many other countries, however, professional obstetric societies have endorsed home birth for low-risk pregnancies.

VBAC is a more risky event than a typical vaginal delivery and is associated with more risks than a repeat cesarean delivery. The risk for uterine rupture is 0.7%, and the risk for hypoxic-ischemic encephalopathy is also increased (absolute risk, 0.46 per 1,000 women at term undergoing a trial of labor). An ACOG practice bulletin states that good and consistent scientific evidence indicates that most women with 1 previous cesarean delivery are candidates for attempting VBAC. However, because uterine rupture may be catastrophic, ACOG recommended that VBAC be attempted only in institutions equipped to respond to emergencies.

Clearly, Mrs R's decision to attempt a VBAC at home is against the ACOG recommendations and is risky for both Mrs R and her fetus. It is not what you would recommend. Informing the parents that you believe that their action is placing Mrs R and the fetus at risk for harm is morally obligatory. The pediatrician should recommend in-hospital delivery for the sake of both the child and the pregnant woman. In the end, however, Mrs R has and should have broad autonomy with respect to her obstetric decisions, and many of these are beyond the purview of the pediatrician.

At the same time, physicians have a right to refuse to participate in treatment that goes against their moral conscience. Refusing to participate in home births would be morally acceptable for physicians. The parents should be given as much information as possible about the risks of uterine rupture and the danger signs. They should be informed about appropriate medical interventions for the newborn, including vitamin K, newborn screening, and hepatitis immunizations. Alternatively, the pediatrician may decide to participate out of concern for the best interest of the newborn. Needless to say, pediatricians should carefully document all discussions about risks and their strong recommendations against home birth. Physicians may want to discuss their decisions with legal or risk-management personnel before participating.

Whether you participate in the home birth or not, Mr and Mrs R may still ask if you are willing to be the pediatrician of their children. The authors of this chapter encourage pediatricians to accept such families into their practices so as to be in a position to advocate for the medical needs of these children. The children will suffer if the medical community abandons them because of their parents' beliefs and

lifestyles. Whether pediatricians agree or do not agree with their parents' obstetric decision, the live newborn and siblings need a medical home.

CONCLUSION

In the medical care of children, ethical conflicts can develop within the family and between the pediatrician and the family, or the pediatrician and family may be in conflict with the state. The preceding cases represent different health care scenarios that will be familiar to everyone who is involved in the primary health care of children. In each case, we consider the range of morally permissible resolutions and propose a stepwise ethical approach to resolve the conflict. The first and most important step is in-depth discussion among physicians, parents, and children to try to understand why people hold the beliefs that they do. Physicians should be open-minded and willing to compromise, up to a point. The second important consideration is some assessment of the benefits and the burdens of the proposed treatment or action and of the available alternatives. Generally, parents have both the legal responsibility and the moral authority to make medical decisions for their children. The pediatrician's respect for the child's opinion should increase as the child grows older, acquires increased capacity to understand and make decisions, and approaches the age of legal majority. In all of the previously mentioned situations, pediatricians must balance their own assessments of what is best for the child with an understanding that children benefit from interacting with their families in an environment that is safe from third-party intrusion. Pediatricians also must remember that their expertise is in deciding what is medically best for a child, whereas parental decisions need to reflect what is best for the child overall, balanced by the parents' right, privilege, and responsibility to preserve their cultural, social, and moral values.

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Chapter 12

EMERGENCY CARE

Karen S. Frush, MD

INTRODUCTION

Pediatricians and other physicians who care for children deliver a variety of services to children and their families, including preventive care, such as immunizations and anticipatory guidance; acute or urgent care at the time of mild or moderate illness or trauma; and, occasionally, emergent care and stabilization of children with possibly life-threatening illnesses or injuries. When a true emergency happens (Box 12-1), pediatricians as well as nonphysician clinicians must be prepared to stabilize the child, rapidly access the emergency medical services (EMS) system for transport to a higher level of care, support the parents and family, communicate with the receiving team in the emergency department (ED), and continue to care for the other children and families in the office at the same time. To perform all these tasks successfully, pediatric office teams must have current training and skills, appropriate equipment and medications, and protocols that help guide each team member with a specific role at the time of the emergency.

PEDIATRIC EMERGENCIES IN THE OFFICE

A number of studies describe the frequency and types of pediatric emergencies that occur in office-based practices. Office-based emergencies involving children have been reported to occur between 2 and 22 times per office per month. Klig and O'Malley suggest that the actual number of emergencies depends on the location and characteristics of the practice. Nearly 65% of pediatricians and family physicians who practice in urban settings reported that they care for at least 1 child who requires hospitalization or urgent care each week, and 80% had cared for at least 1 severely ill patient in the past 3 months. In another study, 51 pediatric offices in a suburban county in the Northeast reported more than 2,400 life-threatening emergencies per year, and 16% of office practices reported 1 to 2 incidents of cardiac arrests per year.

BOX 12-1 Office Emergency

A 9-month-old infant has had a fever, vomiting, and diarrhea for 2 days. The infant was brought to the office today because the mother was having difficulty waking her up. The mother reports that the infant has been sleeping all morning and would not take a bottle. The mother appears very concerned and frightened as she gives this information to the receptionist.

The types of emergency seen in an office vary as well, depending on factors such as the number of children in the practice with chronic illness and special needs, the location of the practice (eg, urban, rural), and the proximity of the practice to the nearest ED. The most common types of office emergency are respiratory emergencies (asthma and obstructed airway), seizures, infections in young infants (including meningitis), shock due to diabetic ketoacidosis (DKA) and dehydration, and head trauma. Pediatricians and other physicians may be required to stabilize children with these conditions in the office and to provide urgent or emergent care at least until the arrival of EMS or local emergency care personnel. The consequences of being unprepared can be devastating; therefore, adequate stabilization and timely transfer to an appropriate facility for definitive care are important responsibilities of every pediatrician and other physician caring for children.

Emergency Response in the Office Setting

Optimal responses to office emergencies require consideration of a range of issues, including the knowledge and skills of the office team, effectiveness of office triage practices and documentation, availability of emergency equipment and medications, and accessibility of resources outside the office, such as the local EMS and ED or pediatric care center. Completion of an office-based self assessment survey is a good first step toward enhancing overall preparedness for pediatric emergencies. One example of such an assessment is shown in Box 12-2.

Preparing the Office and the Team

Good resuscitation knowledge and skills are essential to the delivery of safe, high-quality emergency care to children, but no individual physician or nonphysician clinician can provide adequate care alone. A high-functioning team is required, and each member of the team must be familiar with his or her role at the time of an emergency. For example, the first person to assess children arriving in the office is often the least medically trained employee—the secretary or receptionist. Because the outcomes of children requiring stabilization depend on early recognition of shock and respiratory distress, it is imperative that the front-line team members know what signs and symptoms to look for and how to summon help when they encounter an emergent situation. Nonclinical office staff can be taught about findings that may signal an emergency in a child, such as labored breathing, cyanosis, audible stridor or wheezing, grunting or flaring, depressed mental status, and uncontrolled bleeding.

When an emergency is recognized, a clear response plan should be in place that facilitates notification of the whole team and clarifies the role of each member of the office staff. For example, one individual should be designated to access EMS, and this person should be knowledgeable about the capabilities and level of response provided by the local EMS agency. Cue cards can be posted by the telephone to assist staff in accessing emergency help and providing appropriate information.

Physicians, nurses, and other clinicians in the office should have preassigned roles on the resuscitation

BOX 12-2 Questions to Guide Office Preparedness

1. Have you ever experienced emergencies in your office setting? What were they, and how often have they occurred?
2. What is your office setting (freestanding office, clinic based, health center based, hospital based, other)? Are there resources on site but outside of your office that you could call on during an office emergency (security, other medical or dental professionals in the same building, hospital code team)?
3. What is the emergency readiness of the staff present during those times? Include any training in:
   - First aid and cardiopulmonary resuscitation (CPR)
   - Basic life support (BLS) or advanced life support (ALS)
   - Pediatric advanced life support (PALS)
   - Advanced pediatric life support (APLS)
   - Emergency nurse pediatric course (ENPC)
   - Other continuing medical education (CME)
4. Have nonclinical staff been trained to recognize a potential or actual emergency?
5. Do all staff know how to access the EMS system? Are staff able to give the location of and directions to the office, level of clinical staff present, age and condition of the child (including vital signs if appropriate), desired transport location, and the level of emergency response required (eg, first response, BLS, or ALS)?
6. Have your local EMS providers ever been to visit your office for a nonemergency call or to receive experience in evaluating pediatric patients?
7. What level of provider comes when you call 911: first responder (ie, police or fire department), BLS (basic level EMTs), ALS (paramedics)? Does your local EMS have the necessary equipment and expertise to manage children?

From Massachusetts EMSC Task Force. *Office Preparedness for Pediatric Emergencies*. O'Malley P, ed. 2nd ed. Boston, MA: Massachusetts Department of Public Health; 2002.

team. The physician is usually the leader of the team (runs the code), providing medical direction. The office nurse may assist with procedures and draw up and administer medications or fluids. A clinical aide may assist the care providers, perform chest compressions, help gather equipment and supplies, and comfort the parents and family. The office secretary or receptionist may activate EMS, provide information to patients and families in the waiting room, and record events, as directed, during the stabilization event. To fulfill these roles, each office employee must be adequately trained and have an opportunity to practice his or her roles before an emergency occurs (see Maintaining Readiness/Mock Codes).

The American Academy of Pediatrics (AAP) recommends that all certified pediatric providers (including physicians, nurses, and physician assistants) have basic life support (BLS) training, and a more advanced level of training is encouraged for physicians who practice in settings without ready access to local EMS advanced life support (ALS) services. BLS, Pediatric Advanced Life Support (PALS), and Advanced Pediatric Life Support (APLS) courses are available through many hospitals, EMS systems, and state and local professional organizations. Additionally, online certification and recertification courses are available for physicians and other nonphysician clinicians, and many of these offer continuing education credits along with course certification.

EQUIPMENT AND MEDICATIONS

The clinical team must have immediate access to appropriate equipment and medications to use at the time of an emergency. A child struggling to breathe should have the necessary adjuncts immediately available (ie, a suction catheter when a child vomits and begins to aspirate, or an appropriate-sized mask and self-inflating bag when positive pressure ventilation is required). Equipment and medications can be stored in a resuscitation room where the child is taken to be stabilized; alternatively, the equipment and drugs can be stored in a bag or mobile storage system that can be quickly and easily transported to the site of the stabilization event. Whatever the system in a particular office, all office staff members need to know where resuscitation equipment and medications are located so that no time is wasted in finding them during an emergency.

Pediatricians and other physicians sometimes ask what equipment is required in the office setting. To answer this question, one should consider the population of children being cared for in the office (eg, a large number of children with special needs who might require replacement of a tracheostomy tube or gastrostomy tube) and the proximity to a higher level of care. As an example, for clinicians who practice in an office located in or near a hospital, basic airway equipment may be all that is needed. However, for practices and offices that have prolonged emergency response times, stabilization efforts may need to be maintained for up to 30 minutes before EMS personnel arrive with equipment and stabilization skills. In these offices, more equipment is required to manage an airway and to initiate treatment of shock.

The use of a clinical tool or system to help physicians rapidly determine the appropriate size of equipment and the correct dose of medication is encouraged in the office setting. One such tool, the Broselow pediatric resuscitation tape, has been used in many EDs, EMS services, and offices across the country. Studies have shown that the proper use of the Broselow tape can help decrease the frequency of medication dosing errors and the time it takes to administer medications during an emergency.

Charts or manuals with equipment size and medication dosing (including dose in mg/kg, drug formulation, and volume to administer) organized by patient weight are sometimes available through local hospital EDs, pediatric departments, or pediatric centers, and these resources may be useful to physicians in an office or clinic setting. The AAP Committee on Pediatric Emergency Medicine has provided lists of recommended equipment (Table 12-1) and medications (Table 12-2) for office emergencies.

Table 12-1 Recommended Equipment for Pediatric Office Emergencies

OFFICE EMERGENCY EQUIPMENT AND SUPPLIES	PRIORITY
AIRWAY MANAGEMENT	
Oxygen delivery system	E
Bag-valve-mask (450 and 1,000 mL)	E
Clear oxygen masks, breather and nonrebreather, with reservoirs (infant, child, adult)	E
Suction device, tonsil tip, bulb syringe	E
Nebulizer (or metered-dose inhaler with spacer/mask)	E
Oropharyngeal airways (sizes 00–5)	E
Pulse oximeter	E
Nasopharyngeal airways (sizes 12–30F)	S
Magill forceps (pediatric, adult)	S
Suction catheters (sizes 5–16F) and Yankauer suction tip	S
Nasogastric tubes (sizes 6–14F)	S
Laryngoscope handle (pediatric, adult) with extra batteries, bulbs	S
Laryngoscope blades (0–2 straight and 2–3 curved)	S
Endotracheal tubes (uncuffed, 2.5–5.5; cuffed, 6.0–8.0)	S
Stylets (pediatric, adult)	S
Esophageal intubation detector or end-tidal carbon dioxide detector	S
VASCULAR ACCESS AND FLUID MANAGEMENT	
Butterfly needles (19–25 gauge)	S
Catheter-over-needle device (14–24 gauge)	S
Arm boards, tape, tourniquet	S
Intraosseous needles (16 and 18 gauge)	S
Intravenous tubing, microdrip	S
MISCELLANEOUS EQUIPMENT AND SUPPLIES	
Color-coded tape or preprinted drug doses	E
Cardiac arrest board/backboard	E
Sphygmomanometer (infant, child, adult, thigh cuffs)	E
Splints, sterile dressings	E
Automated external defibrillator with pediatric capabilities	S
Spot glucose test	S
Stiff neck collars (small/large)	S
Heating source (overhead warmer/infrared lamp)	S

E, essential; *S,* strongly suggested (essential if EMS response time is more than 10 minutes).
Adapted from American Academy of Pediatrics Committee on Pediatric Emergency Medicine. *Emergency Medical Services for Children: The Role of the Primary Care Provider*. Singer J, Ludwig S, eds. Elk Grove Village, IL: American Academy of Pediatrics; 1992.

Documentation

Complete and accurate documentation of stabilization efforts in the office is vital for ongoing care, especially at the time of transfer to the ED.

Emergency situations are often difficult to document properly for numerous reasons: stress levels are high, many times there are not enough employees in the office to manage all the tasks, and children and families in the waiting room cannot be ignored. However, every effort should be made to document the date and time of treatment, the estimated or actual weight of the child, medications given with dosages and response noted, fluid types and volumes given, information or explanations given to the family, and the condition of the child at the time of departure from the office. A resuscitation log can serve as a checklist for office staff, and one copy can be sent with the transport team while another copy is kept in the office to refer to during review and debriefing of the event. Sending information about the patient's medical history, including a problem list and a medication list, is also helpful to ED staff.

Emergency Medical Services for Children

Based on military experiences that demonstrated improved survival rates of soldiers stabilized in the field and transported to a well-equipped emergency facility, the EMS system in the United States was formally established in the early 1970s through the EMS Systems Act of 1973. Focused primarily on the needs of adults with life-threatening injuries and medical conditions, the EMS system lacked specific protocols, equipment, and training for providing optimal care in pediatric emergencies. In 1984, the EMS for Children (EMS-C) program was established to ensure that all children and adolescents receive appropriate care at the time of an emergency. The AAP has worked closely with the EMS-C program since its inception to support pediatric emergency care efforts and establish a close collaboration among pediatricians and nonphysician clinicians caring for children.

When a child is brought to the pediatrician's office with a serious illness or injury, the office becomes the entry point to the EMS-C system. The pediatrician and office staff, no matter how well prepared, often need

Table 12-2 Office Emergency Drugs

MEDICATIONS	PRIORITY
DRUGS	
Oxygen	E
Albuterol for inhalation*	E
Epinephrine (1:1,000)	E
Epinephrine autoinjectors	E
Activated charcoal	S
Antibiotics	S
Anticonvulsant agents (diazepam, lorazepam)	S
Corticosteroids (parenteral/oral)	S
Dextrose (25%)	S
Diazepam, rectal	E
Diphenhydramine (parenteral, 50 mg/mL)	S
Epinephrine (1:10,000)	S
Atropine sulfate (0.1 mg/mL)	E
Midazolam, nasal	E
Naloxone (0.4 mg/mL)	S
Sodium bicarbonate (4.2%)	S
Supplies for reconstituting parenteral antibiotics	E
FLUIDS	
Normal saline solution or lactated Ringer solution (500-mL bags)	S
5% Dextrose, 0.45 normal saline (500-mL bags)	S

E, essential; *S*, strongly suggested (essential if EMS response time is more than 10 minutes).
*Metered-dose inhaler with spacer or mask may be substituted.
Adapted from American Academy of Pediatrics Committee on Pediatric Emergency Medicine. *Emergency Medical Services for Children: The Role of the Primary Care Provider.* Singer J, Ludwig S, eds. Elk Grove Village, IL: American Academy of Pediatrics; 1992.

help from community members of the emergency care team. EMS personnel can provide vital support and assistance to the office team during stabilization in the office and ongoing care during transport to the ED. EMS personnel who respond to pediatric emergencies may include professionals with BLS or ALS training. First responders can offer essential BLS skills and transport, whereas ALS emergency medical technicians, acting under medical control and advanced protocols, can perform advanced airway management techniques, including positive pressure ventilation and placing airway adjuncts. They can also establish intravenous or intraosseous access, administer intravenous or nebulized medications, defibrillate, and perform other advanced techniques in accordance with local protocols. In most cases, EMS response to an office emergency will require the deployment of an ALS unit.

Pediatricians should educate patients and families about the emergency response system and teach parents how to recognize an emergency, respond appropriately in terms of first aid, and access the EMS system. Children with serious medical conditions or injuries should not be taken by the family car, taxi cab, or bus to the pediatrician's office, or even to the ED, although parents may sometimes feel this would be faster than waiting for an ambulance. Safe transport requires the presence of trained emergency personnel with the skills and equipment needed to initiate appropriate care at the scene. Similarly, critically ill or injured children should not be sent from the pediatric office to the ED by any form of transport other than EMS. Optimal transport requires trained personnel who can maintain stabilization efforts that were begun in the office.

Deterioration or death of the child during transport without adequate equipment and personnel is the responsibility of the sending physician when nonmedical means of transportation are used, and the benefit of trained personnel and proper equipment during transport outweighs the risk of waiting for EMS personnel to arrive.

Maintaining Readiness/Mock Codes

Full pediatric cardiopulmonary arrest is, fortunately, an extremely rare event in the office setting. Most office emergencies are severe presentations of common pediatric illnesses and diseases, such as asthma, bronchiolitis, DKA, dehydration, head injury, poisoning, or seizures. All of these disorders can become life threatening if not managed appropriately and swiftly in the office.

In any emergency, the ABCs (*a*irway, *b*reathing, *c*irculation) must be addressed immediately. The sooner BLS and ALS maneuvers are initiated, the greater the chance for complete recovery. However, the knowledge and skills required at the time of an emergency are not among those that the pediatrician uses often. The best way to ensure readiness is to practice regularly in the office setting, with as many staff members as possible participating. Simulated exercises, or mock codes, provide a good opportunity for office staff to rehearse for an emergency. High-fidelity simulation with expensive mannequins is not required; indeed, a plastic baby doll can suffice for low-fidelity scenarios. To make the practice sessions more realistic, the scenario should be familiar to office staff (perhaps based on a real event that occurred in the office), and participants should be encouraged to act out each step of the resuscitation. For example, a "parent" comes to the reception area, holding an "infant" (mannequin) and complaining that the infant will not wake up. The receptionist would then need to activate the emergency response system designed for the office, and the nurse would respond as he or she would in a real emergency, perhaps by taking the infant to a treatment room.

Clinical staff should be required to locate specific pieces of equipment that might be needed and demonstrate use of devices (eg, connecting tubing from the oxygen tank to the bag-valve-mask device and demonstrating proper bagging technique). The physical act of locating and handling equipment can help prepare staff to perform these tasks when a true emergency occurs. Team members can offer observations of their own and others' performances, and specific improvement plans can be developed. Studies of mock codes in the office setting have demonstrated that these exercises can lead to enhanced readiness for pediatric

emergencies. It is also important to check the expiration dates of the drugs used for emergencies during the simulation exercises and replace those that have expired.

SUMMARY

Pediatricians provide the services and support necessary for comprehensive health care, ranging from prevention of illness and injury to acute care services and management of chronic disease to critical care and rehabilitation following serious illness or injury. When a child is brought to the office with potentially life-threatening illness or injuries, the office staff must be prepared to provide swift, effective care to ensure the best possible outcome. Delivering optimal care requires coordination and collaboration with emergency care providers in the community and facilitating a safe transition from the office to a higher level of care. By considering these strategies and implementing a plan to improve office preparedness, pediatricians can greatly influence the outcome of an emergency and offer the best chance of intact survival to each child and family.

TOOLS FOR PRACTICE

Medical Decision Support

- *APLS: The Pediatric Emergency Medicine Resource* (Web site), American Academy of Pediatrics, American College of Emergency Physicians, Jones & Bartlett Learning (www.aplsonline.com)
- *Pediatric Office Emergencies* (article), *Pediatric Clinics of North America*, Vol 60, Issue 5, 2013

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SECTION ONE

Pediatric Assessment

Chapter 13
PEDIATRIC HISTORY: ASSESSING THE CHILD

William E. Boyle, MD

> *"A good history carefully obtained from an intelligent mother puts the physician in possession of a fund of information about the patient which is of greatest value, not only in arriving at a diagnosis in the illness for which he is consulted, but is exceedingly helpful in the future management of the child."*
>
> L. EMMETT HOLT, 1908

*Note: Histories may be taken by a variety of persons, including students, residents, nonphysician clinicians (PNPs and PAs), and physicians. For the sake of clarity and brevity, the term "*physician*" will be used throughout this chapter.*

This chapter covers the general interview of a child or family. Specific history taking for adolescents is covered in Chapter 119, Interviewing Adolescents. Specific assessment of the social environment and taking a mental health history are covered in Chapter 14, Pediatric History: Assessing the Social Environment, and Chapter 15, Pediatric History: Assessing Functioning and Mental Health, respectively.

A history is a story told by the patient or the patient's family. It is a unique and personal story in which are embedded the words, phrases, and clues that direct the physician to the general or specific medical concern or problem. The patient or family brings complaints of illness, which the pediatrician must translate into medical theories of disease. Care must be taken so that nothing is lost in translating this personal story into a precise disease entity. It requires the physician to listen to this detailed sequence of events and, through careful direct questioning, to formulate a differential diagnosis. Parents and patients hope the physician will hear their story and interpret it correctly. This task is not easy.

Perhaps in no other medical field is a history as important as it is in pediatrics. Early detection of problems related to health—including growth, development, and nutrition—and prevention of future difficulties relies on the pediatrician's thorough knowledge of the child and the family, including their lifestyle, cultural beliefs, and environment. Unlike most other areas of medicine, the pediatric history may be given by someone other than the patient. Thus, a certain amount of subjectivity and objectivity are lost. Signs and symptoms are filtered through parental perspectives before emerging as historical data, and these perspectives are influenced by parental hopes and fears. A pediatric history is a compilation of information gathered in a variety of ways through interviews, direct observations, questionnaires, and medical records that usually provides a concise record of the child and the family.

In the past, training in interviewing and history taking took place for an acute problem in which the concern or complaint was readily stated or easily seen. Today, however, children and adolescents are seen for an increasing number of problems outside of the hospital. These may include learning difficulties, chronic or disabling conditions, or behavioral or developmental concerns, all of which require sensitive, insightful listening. The pediatrician must have a thorough knowledge of the child's health status, developmental stage, and cognitive level, as well as the family's functional characteristics, belief systems, and socioeconomic circumstances. Much of pediatrics deals with vague questions or concerns such as "Why does she cry so much?" "Why is he so thin?" or "Is that cough serious?" These concerns must be answered and expectations managed if the encounter is to be fruitful. If the parent or patient and physician have different perceptions of the problem, then the physician must attempt to tease out and understand the patient's or the parent's concerns. The parent or patient may be worried about something tangential to the chief complaint; this situation is sometimes referred to as the *second diagnosis*.

Children and their families are diverse, and they bring with them a wide variety of cultural beliefs and customs. Physicians must be aware that their own belief systems may differ from those of the patient and family and try to make accommodations. Questions should be asked about what the family thinks caused the illness or condition and what treatments were attempted before seeing the physician. By understanding the patient and family's perception of the illness or condition, the physician can develop expectations of treatment and outcomes.

Much transpires during the initial interview between a pediatrician and a family other than the gathering of a history. The tone of all future encounters is established, and, ideally, the family begins to develop a trusting, confident relationship with the pediatrician. Just as the pediatrician is trying to assess the problem at hand, so too are the parents (and child) *sizing up* the clinician. A warm, friendly, nonjudgmental, courteous manner facilitates a good relationship. Taking a history requires some degree of decision-making on the part of the interviewer as

to what is relevant. Taking a history is not merely gathering a list of all symptoms and pertinent historical *negatives*; it involves the synthesis of various facts, attitudes, and observations. To perform this task well requires experience, tact, and a degree of intuition. The task is difficult. A history is compiled best if, for each visit, the pediatrician can obtain the answers to 3 questions:

1. "Why did you come today?"
2. "What are you worried about most?"
3. "Why does that worry you?"

Answers to these questions not only direct further inquiry, but also provide clues to parent and patient concerns that need to be allayed or dealt with directly during the visit and, perhaps, thereafter. For example, a parent who brings a child to a physician because of swollen cervical lymph nodes may be worried that they have a malignancy because an aunt who died of Hodgkin disease had the same problem. Parents, older children, and adolescents need to be told what symptoms and signs do *not* represent, as well as what they do represent, especially if they are worried that the symptoms and signs indicate a serious or fatal illness.

SETTING AND AMBIANCE

Pediatric histories are taken in a variety of locations, and a comfortable environment enhances communication. If the physician is courteous, interested, and helpful, then a trusting, positive relationship is likely to develop. Patients and parents are acutely aware of what the physician thinks of them or what they perceive the physician's opinion of them to be; this perception is termed the *reflexive self-concept*. ("The doctor thinks I'm a good parent.") If the reflexive self-concept is high, then parent (or patient) satisfaction and compliance with recommendations for management are more likely to be high. Some questions to consider are:

- Does the pediatrician imply disinterest in the patient by cutting short the parent's description or allowing constant interruptions during the history taking?
- Is privacy ensured?
- Are children made comfortable?
- Is there a place for clothing and belongings (other than a lap)?

Obviously, seating should be available for all, and the history taker should remain seated for the session. The pediatrician should strive to maintain eye contact and not constantly view a computer screen or notes. Parents or guardians should be called by their formal names (Mrs. Williams, Mr. Adams), unless a personal relationship has been established that enables the use of first names. Children should be referred to by their first names rather than *he, she*, or *the infant*. Notes can be taken as long as doing so does not distract from the continuity or spontaneity of the interview. Most parents find that coping with more than one child is disruptive and distracting; therefore, seeing more than one child at a time should be discouraged. Toys or books should be available to help occupy infants and toddlers, if necessary.

Clothing and appearance may affect the ease with which a relationship is established. Parents and children view a visit to the pediatrician as a special occasion and frequently dress accordingly. They hope their physician will view the visit in the same manner. The physician's dress should be appropriate and consistent with local norms. Most pediatricians do not wear a white coat because it may evoke fearful memories for the child, although this notion has never been substantiated. Whatever the attire, a sense of competence must be conveyed.

TYPES OF INTERVIEWS

The initial history may be taken during an interview with the parents before their infant's birth, in the hospital after the birth, in the physician's office during the visit for whatever reason, in an emergency department at the time of an acute illness, or in a hospital room after admission for a specific illness or elective surgery. The time devoted to the initial interview and the amount of information gathered depend on the circumstances. Similarly, subsequent history taking will vary in depth and breadth, depending on the reason for the visit and the amount of time that has elapsed since the last visit.

This chapter focuses on the information to be gathered and the techniques used in obtaining the comprehensive pediatric history. Circumstances may preclude completion of this exercise during the initial visit. For example, the initial history obtained for a child who has acute otitis media and who is squeezed in during fully scheduled office hours will be brief and relate primarily to the chief complaint. The rest of the history can be obtained during a scheduled follow-up visit.

Prenatal Interview

Ideally, the parents should have their first encounter with a pediatrician before their infant is born. To many people, the idea of bringing an infant in utero to the pediatrician seems strange, but much information can be gathered at this time, and a strong, understanding relationship between the parents and the pediatrician can be fostered. Furthermore, some issues can be addressed before the postpartum period. For example, a pregnant woman with little psychosocial support may be identified and appropriate aid offered. In addition, society in the United States is mobile; most young couples live alone and are often far removed from parents and siblings, and they often turn to professionals for support and assistance.

Obstetricians traditionally care for women only throughout pregnancy and the immediate postpartum period. Pediatricians traditionally assume care of the infant at birth. Many women find difficulty in leaving someone who has supported them through a difficult psychobiologic change and developing a new relationship while they learn the new role of motherhood. A prenatal interview can greatly assist in this transition.

Prenatal interviews do not need to be long or detailed; 20 to 30 minutes should suffice. In addition to gathering facts, the pediatrician should set a tone for future encounters. Prospective parents should be interviewed together, if possible, so that parental concerns can be aired, and they can be helped to support each other. Parents are anxious about their adequacy and the health of their unborn infant, and a supportive attitude and tacit acknowledgment that these fears are understandable can be helpful.

A thorough family history is a way of showing concern, not just for the child but also for the entire family. Parents should understand the physician's interest in them as individuals and not merely as Teddy's or Sarah Jane's mother and father. The prenatal interview provides an excellent opportunity to inquire about belief systems and cultural values.

During a typical prenatal interview, plans for labor and delivery should be discussed, as well as a program of childbirth education and the type of infant feeding that is contemplated, indicating the many advantages of breastfeeding. Pointing out certain safety issues to which the parents should attend is wise at this time, before their infant comes home, such as obtaining a child safety seat and a smoke detector and setting the hot water heater at a safe temperature (see Chapter 42, Safety and Injury Prevention). Also, the pediatrician should ask about the age of the home and if there may be a risk for exposure to lead, which should be eliminated. Many couples will already know the sex of their unborn child through prenatal ultrasound. Circumcision should be discussed, if they know they are having a boy. If blood tests (newborn screening), immunizations (for hepatitis B virus), or vitamin K administration will be performed, then these subjects should be described and discussed.

The mother's blood type, medications taken, and rubella and HIV status (if known) should be elicited. Genetic information should be gathered about both sets of grandparents. In addition to inherited disorders and birth defects, familial tendencies such as obesity, hypertension, and short stature should be investigated. Asking what the couple's own parents were like is also wise because parenting techniques and cultural beliefs are frequently passed from one generation to the next. Parents should also be encouraged to update their Tdap and influenza immunizations as appropriate.

After dealing with the family history, the physician needs to gather some information about other supportive individuals. Who will help out when the infant comes home? Who will be the main caregiver? Will the father have a paternity leave of some sort? Will the mother be returning to work? if so, when? Who will be caring for their infant? Grandparents traditionally visit shortly after delivery, and the pediatrician should point this out and ask if they will be helpful or a burden. The pediatrician should also inquire if transportation and a telephone are readily available. The physician should be alert at all times for evidence of undue stress, isolation, and prior psychosocial issues such as maternal depression or drug abuse because these factors are known to be predictors of poor parenting. The parents will want to know when the pediatrician will see the infant in the hospital, what the appointment schedule will be, and how the pediatrician can be reached. Fees and payment options for visits can also be discussed at this time.

The parents should be allowed to ask questions about their concerns. Cultural beliefs and values should be explored. Supporting their instincts, rather than directing and showing the pediatrician's own personal bias, is best. The pediatrician should anticipate certain normal variations such as sleepy infants, the postpartum "blues," and the physiologic slump that lasts from 6 to 8 weeks after birth. Parental questions may seem trivial (skin care, type of diapers), but they all revolve around the question, "Will we be good parents?" Strong reassurance that their instincts are good serves to reinforce and strengthen the couple's tendencies toward good parenting and leads to a confident beginning as parents.

At the conclusion of the interview, the physician should have an idea of the parents' lifestyle and coping mechanisms, and the parents should feel reassured that they have a supportive person who will help them enter parenthood.

As prenatal interviewing has become more widespread, interview requests for second or subsequent pregnancies have become more common. These sessions are generally not quite so formal and can take place during the routine health maintenance visits of an older child. Parental concerns deal not only with the health and soundness of the unborn but also with coping with another child. "Will I be able to divide myself and still survive?" The mother may find herself torn between her infant in utero and her older infant. Parental or caregiver efforts to push the older child into relinquishing diapers, crib, stroller, or high chair should be discouraged. Separation at the time of delivery can be a problem for a child, who must be told that his or her mother will leave for a while and then return. This separation should occur shortly before the expected delivery. The separation will also stress the supports that the family has developed, and the physician should review these at this time. Recounting any previous birth experience is similarly important so that conflicts or problems may be identified and thus prevented.

Comprehensive Pediatric History Interview

Traditionally, history taking has been a stepwise delineation of the events that led to the physician-patient encounter. Most clinicians learn this technique while dealing with hospitalized or acutely ill children, in a location where the problem frequently is visible or obvious. Fortunately, a great deal of history taking now occurs in settings other than the hospital and frequently does not involve illness; this is termed the *pediatric history interview*. History taking is merely a part of the interview, which should include observation of behavior and family interactions. Essentially, a history is a story about an encounter between physician and parent and child that includes subjective and objective data and omits some details considered irrelevant.

Box 13-1 is a suggested outline for components of a comprehensive pediatric history. In certain settings, some of the data will have already been gathered, but a thorough knowledge of each component of the history is essential.

Usually, the interview begins with the parents stating the concerns that led to the present encounter—the *chief complaint*. The parents should be allowed, with as little interruption as possible, to relate their story as they recall it. Certain areas may be amplified and clarified, but direct or challenging questions should be avoided. After eliciting the chief complaint,

BOX 13-1 Comprehensive Pediatric History

The following comprehensive pediatric history is exhaustive and not meant to be used in its entirety with all patients. However, depending on the patient's age and gender and the nature of the chief complaint and the present illness, the interviewer will need to explore in depth some or all of the subjects listed. In most instances, common sense must be used in deciding how much information should be gathered.

Date of interview

Identifying data: Record the date and place of birth, gender, race, ethnicity, parent living arrangements, religious preference, nickname (particularly for children 2 to 10 years of age), parents' first names (and last names, if different), and where the parents can be reached during work hours.

Source of and reason for referral

Source of the history: This source may be the parents, the patient, or sometimes a relative or friend. The physician should use judgment of the validity of the source's reporting. Other possible sources of the history are the patient's medical record or a letter from a referring physician or the school nurse.

Chief complaints: When possible, quote the parents or the patient. Clarify whether these complaints are the concerns of the parents, the patient, or both. In some instances, they are the concerns of a third party, such as a teacher.

Present illness: This condition should be a clear, chronologic narrative of the problems for which the patient is seeking care. Include the onset of the problem, the setting in which it developed, its manifestations and treatments, its impact on the patient's life, and its meaning to the patient or the parents, or both. Describe the principal symptoms in terms of location, quality, quantity or severity, timing (ie, onset, duration, frequency), setting, factors that have aggravated or relieved these symptoms, and associated manifestations. Relevant data from the patient's chart, such as laboratory reports, also belong in the *present illness* section, as do significant negatives (ie, the absence of certain symptoms that will aid in differential diagnosis). Include how each member of the family responds to the patient's symptoms, their concerns about them, and whether the patient achieves any secondary gains from them.

Medical history: General state of health as the parents or patient perceives it. Other medical and dental providers of the child (names and contact info).

Birth history: This information is particularly important during the first 2 years of life and when dealing with neurologic and developmental problems. Review the hospital records if preliminary information from the parents indicates significant difficulties before, during, or after delivery.

Prenatal history: Determine the mother's health before and during the pregnancy, including nutritional patterns and specific illnesses related to or complicated by the pregnancy; doses and duration of all legal and illegal drugs taken during the pregnancy, including alcohol ingestion and cigarette smoking; weight gain; vaginal bleeding; duration of the pregnancy; and the parents' attitudes toward the pregnancy and parenthood in general and toward this child in particular.

Natal history: Determine the nature of the mother's labor and delivery, including degree of difficulty, analgesia used, and complications encountered; birth order, if a multiple birth; and birth weight.

Neonatal history: Determine the onset of respiration; resuscitation efforts; Apgar scores and estimation of gestational age; specific problems with feeding, respiratory distress, cyanosis, jaundice, anemia, convulsions, congenital anomalies, or infection; the mother's health after delivery; separation of the mother and infant and the reasons for the separation; the mother's initial reactions to her baby and the nature of bonding; and patterns of crying and sleeping and of urination and defecation.

Feeding history: This information is particularly important during the first 2 years of life and in dealing with problems of undernutrition and overnutrition. Document access to and volume of intake of fluoridated water. The history may require an environmental assessment including lead screening (see Chapter 19, Environmental Health: The Role of the Primary Care Physician).

Infancy:

Breastfeeding: frequency and duration of feedings, use of complementary or supplementary artificial (formula) feedings, difficulties encountered, and time and method of weaning. Family and work support for breastfeeding

Artificial (formula) feeding: type, concentration, amount, and frequency of feeds; difficulties encountered (regurgitation, colic, diarrhea); and timing and method of weaning.

Vitamin, iron, and fluoride supplements: type, amount given, frequency, and duration.

Solid foods: types and amounts of baby foods given, when introduced and infant's response, introduction of junior and table foods, start of self-foods, start of self-feeding, and the parents' and child's responses to the feeding process.

Childhood:

Eating habits: likes and dislikes, specific types and amounts of food eaten, parents' attitudes toward eating in general and toward this child's undereating or overeating, and parents' response to any feeding problems. Does the child and family eat in front of the TV? With childhood feeding problems, the parents may need to keep a diet diary for 7 to 14 days to allow accurate assessment of the child's food intake.

Growth and development history: This history is particularly important during infancy and childhood and in dealing with problems such as delayed physical growth, psychomotor and intellectual retardation, and behavioral disturbances.

Physical growth: Determine the actual (or approximate) weight and height at birth and at 1, 2, 5, and 10 years; record any history of slow or rapid gains or losses; and note the tooth eruption and loss pattern.

Developmental milestones: Determine the ages at which the patient held head up while prone; rolled over from front to back and back to front; sat with support and alone; stood with support and alone; walked with support and alone; said first word, combinations of words, and sentences; tied own shoes; and dressed without help.

Social development:

Sleep: amount and patterns during the day and at night; bedtime routines; type and location of bed; and nightmares, terrors, and somnambulism.

BOX 13-1 Comprehensive Pediatric History—cont'd

Toileting: methods of training used, when bladder and bowel control were attained, occurrence of accidents or of enuresis or encopresis, parents' attitudes, and terms used in the family for urination and defecation (important to know when a young child is admitted to the hospital).

Speech: hesitation, stuttering, baby talk, lisping, and estimate of the number of words in the child's vocabulary.

Habits: bed rocking; head banging; tics; thumb sucking; nail biting; pica; ritualistic behavior; media usage or consumption; and use of tobacco, alcohol, or drugs.

Hygiene: Frequency of toothbrushing. Use and amount of fluoridated toothpaste.

Discipline: parents' assessment of child's temperament and response to discipline; methods used and their success or failure; negativism; temper tantrums; withdrawal episodes; and aggressive behavior.

Schooling: experience with child care, nursery school, and kindergarten; age and adjustment on entry; current level of parents' and child's satisfaction; academic achievement; and school's concerns.

Sexuality: relationships with members of the opposite gender; inquisitiveness about conception, pregnancy, and girl-boy differences; parents' responses to child's questions and what they have taught the child about masturbation, menstruation, nocturnal emissions, the development of secondary sexual characteristics, and sexual urges; and dating patterns.

Personality: degree of independence; relationships with parents, siblings, and peers; group and independent activities and interests; congeniality; special friends (real or imaginary); major assets and skills; and self-image.

Childhood illness: Determine the specific illnesses the child has had, as well as any recent exposures to communicable diseases.

Immunizations: Record the specific dates of administration of each vaccine so that a booster program can be maintained throughout childhood and adolescence; also record any untoward reactions to a vaccine. The parents should have their own written record of the child's immunizations. This may be supplemented by obtaining information from the state immunization registry, if available.

Screening procedures: Record the dates and results of any screening tests. Refer to the AAP Periodicity Schedule or the Bright Futures guidelines to determine which tests to perform at each health assessment visit.

Operations, injuries, and hospitalizations: Elicit the details of these events and the child's and the parents' reactions to them. If the child is old enough, then ask age-appropriate questions about safety and prevention of injuries.

Allergies: Pay particular attention to the allergic diseases that are more prevalent during infancy and childhood: eczema, urticaria, perennial allergic rhinitis, asthma, food intolerance, and insect venom hypersensitivity.

Current medications: Include home remedies, alternative medicines, nonprescription drugs, and medicines borrowed from family members or friends. If the patient appears to be taking one or more medications, then survey one 24-hour period in detail: "Take yesterday, for example. Starting from when he woke up, what was the first medicine Thomas took? How much? How often during the day did he take it? What is he taking it for? What other medications?"

Family history: Record the education attained, job history, emotional health, and family background of each parent or parent substitute; the family's socioeconomic circumstances, including income, type of dwelling, and neighborhood; parents' work schedules; family cohesiveness and interdependence; history of domestic violence; support available from relatives, friends, and neighbors; ethnic and cultural milieu in which the family lives; and parents' expectations of the patient and attitudes toward the child in relation to siblings. (All or part of this information can be recorded in the *present illness* section, if pertinent to it, or under *psychosocial history*.)

Also record the age and health or age and cause of death of each immediate family member, including the parents and siblings (Figure 13-1). Ascertain consanguinity of the parents by inquiring if they are related by blood.

Note the occurrence in the family of any of the following conditions: diabetes, tuberculosis, heart disease, high blood pressure, stroke, kidney disease, cancer, arthritis, anemia, headaches, mental illness, dental disease (decay or periodontal disease), or symptoms resembling those of the patient.

Psychosocial history: This information is an outline or narrative description that captures the important and relevant information about the patient as a person: the patient's lifestyle, home situation, and significant others.

Typical day: How does the patient spend time between arising and going to bed? Parents' marital status, visitation arrangements, support; delineate caregivers for child during day.

Religious and health beliefs of the family: What beliefs of the family are relevant to the perceptions of wellness, illness, and treatment?

What is the patient's outlook on the future?

For more on the psychosocial history, see Chapter 14, Pediatric History: Assessing the Social Environment. For adolescent patients, see Chapter 119, Interviewing Adolescents.

Review of systems:

General: Usual weight, recent weight change, weakness, fatigue, fever, pallor.

Skin: Rashes, lumps, itching, dryness, color change, changes in hair or nails.

Head: Headache, head injury.

Eyes: Vision, glasses or contact lenses, last eye examination, pain, redness, excessive tearing, double vision.

Ears: Hearing, tinnitus, vertigo, earaches, infection, discharge.

Nose and sinuses: Frequent colds, nasal stuffiness, hay fever, nosebleeds, sinus trouble.

Mouth and throat: Condition of teeth and gums, bleeding gums, last dental examination, frequent sore throats, hoarseness.

Neck: Lumps in the neck, swollen glands, goiter, pain in the neck.

Breasts: Lumps, pain, nipple discharge.

Respiratory system: Cough, sputum (color, quantity), hemoptysis, wheezing, asthma, bronchitis, pneumonia, tuberculosis, pleurisy; results of last chest roentgenogram.

Continued

BOX 13-1 Comprehensive Pediatric History—cont'd

Cardiac system: High blood pressure, rheumatic fever, heart murmurs; dyspnea, cyanosis, edema; chest pain, palpitations; results of past electrocardiograms or other heart tests.

Gastrointestinal tract: Trouble swallowing, loss of appetite, nausea, vomiting, hematemesis, indigestion; frequency of bowel movements, change in bowel habits, rectal bleeding or black, tarry stools, constipation, diarrhea; abdominal pain, food intolerance, excessive passing of gas; jaundice, hepatitis.

Urinary tract: Frequency of urination, polyuria, nocturia, dysuria, hematuria, urgency, hesitancy, incontinence, urinary tract infections.

Genitoreproductive system—male patients: Discharge from or sore on penis, history of sexually transmitted infection and its treatment, hernias, testicular pain or masses, birth control method, any children, frequency of intercourse, libido, sexual difficulties, sexual preference, sexual practices. (Use HEADSSS Assessment in Chapter 119, Interviewing Adolescents.)

Genitoreproductive system—female patients: Age at menarche; regularity, frequency, and duration of periods; amount of bleeding, bleeding between periods, last menstrual period; dysmenorrhea; discharge, itching, venereal disease, and its treatment; number of pregnancies, number of deliveries, number of abortions (spontaneous and induced); complications of pregnancy; birth control methods; frequency of intercourse; libido; sexual difficulties; sexual preference; sexual practices (see HEADSSS Assessment in Chapter 119, Interviewing Adolescents).

Musculoskeletal system: Joint pains or stiffness, arthritis, backache; if these conditions are present, then describe location and symptoms (eg, swelling, redness, pain, stiffness, weakness, limitation of motion or activity), muscle pains, or cramps.

Neurologic system: Fainting, blackouts, seizures, paralysis, local weakness, numbness, tingling, tremors, memory loss.

Psychiatric issues: Nervousness, tension, anxiety, moodiness, depression, emotional stressors.

Endocrinologic issues: Thyroid trouble, heat or cold intolerance, excessive sweating, diabetes, and excessive thirst, hunger, or urination.

Hematologic issues: Anemia, easy bruising or bleeding, past transfusions and possible reactions to them.

Modified from Bickley LS, Hoekelman RA. Interviewing and the health history. In: Bickley LS, Hoekelman RA, eds. *Bates' Guide to Physical Examination and History Taking*. 7th ed. Philadelphia, PA: JB Lippincott; 1999. Used with permission.

the physician should enumerate the events associated with it in an orderly sequence *(present illness)*. In addition to facts, parental concerns and feelings about these symptoms should be elicited. The parents should be asked to speculate on what they think is causing the complaint or symptom. This information can be valuable in several respects. First, it demonstrates the level of parental concern, which may influence subsequent care and treatment. Thus parents who equate nosebleeds with leukemia, for instance, will need more than simple reassurance. Second, parental concerns about causation may color the history a great deal; for example, their concern about developmental delay can influence the information they supply about achievement of early milestones. Third, cultural bias or guilt as to causation may exist and should be addressed. Discovering how the present illness affects the rest of the family is always important. Who misses work? Who loses sleep? This information will help the physician better understand the family's concerns about and responses to a given symptom or illness and what, if any, secondary gain exists for the child.

Although the chief complaint must remain the central focus of the interview, it is frequently obvious that this complaint is not the main problem. This circumstance is especially true when dealing with very young children. Tired, anxious, or frightened parents often perceive their reactions to an infant as being abnormal in some way; they then project this perception as something being wrong with the infant, which makes seeking help acceptable. Once the physician recognizes this perception, an attempt should be made to create an atmosphere that allows the parents to express all their concerns. Questions such as, "Are there any other problems with Kathy you would like to discuss?" or "Is there anything else bothering you about Connor?" might facilitate communication.

After the present illness has been defined and elaborated, certain significant events should be enumerated *(medical history)*. Much of this material is factual and can be obtained by using a direct question-and-answer format. Significant events such as operations, serious injuries, and hospitalizations should be verified by obtaining and reviewing appropriate hospital records.

When obtaining the patient's early history, the physician should elicit medically significant facts from conception to the onset of the present illness. All areas delineated in Box 13-1 should be touched on to some degree. The amount of information obtained may vary, but prenatal problems such as bleeding, eclampsia, or infection should be noted, and birth weight, type of delivery, and neonatal problems, if any, should be described. Information about nutrition can reveal a great deal about family dynamics and parental perceptions and expectations. "Tell me how Jennifer eats" frequently brings forth a torrent of information; but its value, nutritionally speaking, may be limited. "Good eaters" and "picky eaters" frequently weigh the same, and children who "hardly eat a thing" are often overweight.

In dealing with issues of development, asking an indirect question such as, "Tell me what Ann did during her first (or second) year" is frequently best. This inquiry usually elicits much more information

than do direct questions about motor milestones. The physician should seek information concerning the level of skill rather than the age of achievement; for example, knowing that the child might make simple wants known at 2 years of age is more important than the age when the first word was uttered. Some information about social adaptability and temperament should be obtained (see Chapter 14, Pediatric History: Assessing the Social Environment, and Chapter 119, Interviewing Adolescents).

Previous health care is important, and the child's immunization status is a significant part of the early history. The physician should record all immunizations, skin tests, and pertinent screening information on a separate sheet that is readily accessible and retrievable. Filling out a few history forms later for camp or entry into preschool will prove the value of this record. A list of current and past medications used, including prescription, nonprescription, and homeopathic remedies, should be obtained.

Allergies and allergic reactions to medications are also an important part of the early history. Specific allergic reactions should be described in as much detail as possible. Medications that cause vomiting or diarrhea are numerous but not usually allergenic. Idiosyncratic reactions to drugs such as amoxicillin and phenothiazides should also be described.

The *family history* contains variable information but is often difficult to construct. An attempt should be made to trace back at least 2 generations on each side of the family. Figure 13-1 shows one method of recording such data. The names, birth dates, and health of the 3 generations concerned are usually listed below the pedigree (although not shown here), using a number indicating each person. As more data such as births, deaths, and disease become available, they can be added easily.

Consanguinity of parents should be investigated specifically by asking if the parents are related by blood. In addition to seeking known inherited diseases such as diabetes, hemophilia, or neuromuscular disorders, the clinician should note familial tendencies such as obesity, short stature, early heart disease, and hypertension. Inquiring about the parenting techniques of forebears is sometimes appropriate. Research has shown that abusive parents were frequently deprived or abused themselves as children. Asking specifically about the health of the parents' brothers or sisters is also important because these individuals are often overlooked during an interview.

The *psychosocial history* describes the child's present milieu and relationships with family, peers, school, and community. This history should include information about the physical setting (eg, housing), environment, media use, and degree of isolation. Important points to determine include how children spend the day, who cares for them, what they like to do, and what their hobbies are. Inquiry should be made about the support system within the family, for example, the nature of an extended family, supportive or conflicting roles, the elements of stress that exist for this child, and how the child and family cope with them.

The psychosocial history should also touch on the parents' attitudes toward discipline and expectations

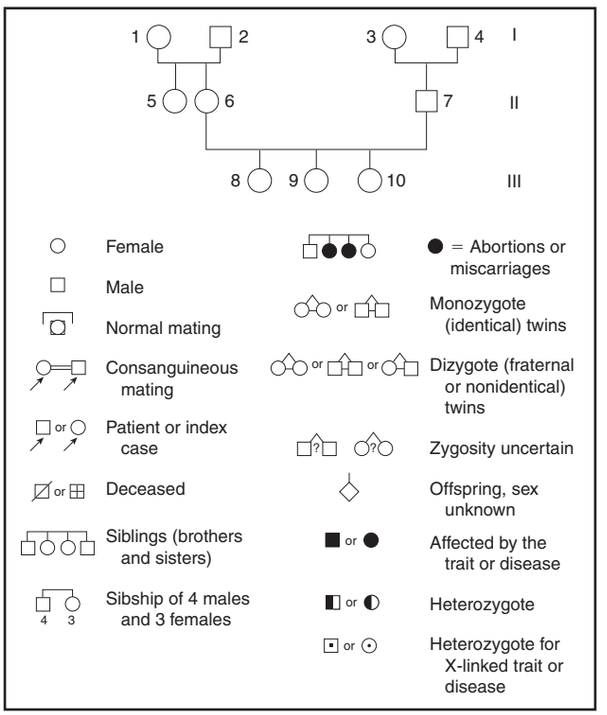

Figure 13-1 Chart and symbols used to construct a family history, or family pedigree. The Roman numerals indicate generations; the Arabic numerals indicate specific persons.

about achievement. When appropriate, the physician should determine how the parents compare this child to the child's siblings or to other children. Asking the parents to describe the child's temperament (eg, "mellow," "feisty," "lazy"), as well as what they see as the child's strengths, is also helpful.

The *review of systems* should be detailed to obtain a baseline evaluation of all systems and their level of function. Children change over time, and various systems may be the target of stress or disease processes. Therefore, the clinician should reassess all organ systems periodically and record their apparent level of function.

INTERVIEWING TECHNIQUES

Clarifying certain terms is essential. For example, *diarrhea* and *flu* mean different things to different people, and no true communication can occur until such terms are defined. *Tired* may mean sleepiness, fatigue, or true lethargy. The temporal nature of complaints must also be assessed carefully. Children who are "always sick" may have recurrent infections that clear in 5 to 7 days, or they may have a perpetually runny nose, which is seen in some children who have allergies.

If the patient has been seen before, then the physician should review the child's medical record before the visit to refresh the memory on past health and illnesses that may relate to the reason for the current

visit. Consultants should review the letter of referral and the reason for and goals of the visit before interviewing the parents and patient.

Many parents see their skills as parents being challenged during the pediatric interview: "After all, if we did things right, we wouldn't need to see the doctor." They become defensive and may answer questions *ideally*. At the same time, they want to share fears and worries with someone who is caring and empathetic. The pediatrician must strive to develop this trusting relationship. By being facilitative, the physician enables the parents to express fears and frustrations. Statements such as "That must have worried you" or "I bet that's upsetting" let parents know that the physician is concerned with much more than the facts in the interview. On the other hand, statements or questions suggesting that the parents have not managed their child's illness properly such as "You should have brought Gretchen in sooner," or "It would have been better not to have fed Stephanie," or "Why did you do *that*?" should always be avoided.

The techniques used to obtain a complete and accurate history vary with the situation and the person being interviewed.

Types of Questions

In emergencies, the physician should ask only direct (not open-ended) questions that quickly elicit the important facts needed to make decisions regarding treatment. In nonemergencies in which time is not a factor, direct questions should be used to obtain identifying data and concerns. In nonemergency situations, having the parent or child tell the story without interruption is best. Time will dictate how much additional information is obtained.

Direct questions should be asked one at a time. Rapid-order direct questions such as "Has Karl ever had eczema, hay fever, asthma, or allergic reactions to drugs?" are logical to the questioner but are likely to confuse the respondent and lead to an overall "no" answer when a "yes" would be appropriate for one or more of the elements of the question.

Indirect (open-ended) questions are extremely useful in eliciting the present illness and psychosocial history. The answers to open-ended questions such as "How does Bonnie spend a typical day?" often provide clues to underlying, unstated problems and cues for pursuing specific elements of the patient's illness.

Direct questions are also important in eliciting the details of the present illness and the psychosocial history. For example, if a cough is mentioned as a symptom in the patient's illness, then the following sequence of direct questions is appropriate: "How long has Kathy had the cough?" "When does she have it?" "Does it wake her up at night?" "What does it sound like?" "Does she cough up any phlegm?" "How much?" and "What does it look like?" Thus, open-ended questions identify the direction for further inquiry, and direct questions help determine the importance of the symptoms or signs identified.

Leading, direct questions such as "Does Jane do well in school?" should be avoided because they are more likely to result in *expected*, affirmative answers than are nonleading, direct questions such as "What kinds of grades does Jane get in school?"

Helping the Parent or Patient Communicate

Throughout the interview, the parents or patient should be assisted in several ways to relate all necessary information fully. The pediatrician should use medical terminology the parents or the patient understands. Words such as *tinnitus, palpitation,* and *incontinence* may have little meaning to the parents or patient, who will often be too embarrassed to ask for a definition and may simply answer "no" when asked if these signs and symptoms are present.

The interview process is one of interaction between the physician and the parents or patient. The person providing information should do most of the talking, and the physician should do most of the listening. However, the physician can encourage the parents or patient to communicate the story by using the following 7 techniques:

1. *Facilitation*. This technique is designed to convey interest in what the parent or patient is saying. Maintaining eye contact, leaning forward, nodding in affirmation, and saying "yes," "uh huh," "I see," and similar responses all convey interest and encourage the parent or patient to continue. Additional information might be gained by giving an example, such as "In other situations like this, some parents have thought of alternative medicines. Have you thought so too?"
2. *Reflection*. Repetition of words the parent or patient has said encourages the provision of more detail, as is demonstrated in the following example:
   Parent: "Kara woke up in the middle of the night breathing hard."
   Interviewer: "Breathing hard?"
   Parent: "Yes. She seemed to be breathing fast and making a wheezing noise."
   Interviewer: "A wheezing noise?"
   Parent: "Yes, in and out—a musical wheezing sound."
   By using reflection, the interviewer was able to elicit the nature of the child's breathing difficulty without influencing its description or diverting the parent's thoughts.
3. *Clarification*. The interviewer must often clarify what the parent or patient has said, for example, "What do you mean by 'Rob wasn't acting right?'"
4. *Empathy*. Recognizing and responding to a parent's or a patient's feelings of concern, fear, or embarrassment shows understanding and acceptance and encourages continued expression of the emotion. "I can understand why that upset you" or "That must have been difficult to deal with" is an empathetic expression that tells the parent or patient that the physician appreciates what the parent or patient has been experiencing and is sympathetic. The physician can also ask how the parent or patient feels or felt about a particular situation that has been related. This question displays an interest in the parent's or the patient's feelings, as well as an interest in the medical facts.
5. *Confrontation*. This technique is used to clarify what seems to be a contradiction between the parent's or the patient's feelings and actions: "You say that Alison loves school but misses a lot because she has an upset stomach most mornings." Although confrontation is used to seek clarification, it may also

lead to interpretation of the meaning of the contradiction.

6. *Interpretation*. This technique is used to move beyond clarification to an inference to be made from the circumstances presented. Thus, the previous example might lead to the following statement and questions by the physician: "Maybe there is some relationship between Alison's upset stomach and her wanting or not wanting to go to school. Do you think that's possible?"
7. *Recapitulation*. This technique is especially useful when a long and complicated history or an unusual history is presented. The physician summarizes to the parent or patient the history as the physician understands it. This task may be done at more than one point during the interview and serves to confirm the validity of the history; it also allows for possible changes.

Toward the end of the interview, asking the question, "Is there anything else you think I should know?" is sometimes helpful. This open-ended inquiry leaves parents with the sense that things were not rushed and that room still exists for discussion.

Hindrances to Communication

Although a calm, reserved, interested demeanor is important to enhance communication, the physician must guard against appearing casual. Constant eye contact with the parent, interrupted by glances at the child (if present), should be maintained. Evidence of boredom or impatience—looking away from the parents or patient, tapping the fingers or a pencil on a tabletop, or rushing through the interview—must be avoided. Laptop computer records of the patient should be reviewed beforehand and not during the interview. Inappropriate smiling or laughter also hinders good communication. The parents or patient always should believe that they have the physician's undivided attention. If time is short, then the parents or patient should be informed and another appointment made for completing the interview.

Interviewing the Child

A great deal of information can be gained by interviewing the child directly. Many children interact spontaneously with the pediatrician and answer direct questions readily. In many instances, only the child can reveal the severity of the pain or the extent of the symptoms. Approaching children indirectly, encouraging them to talk about their symptoms, is sometimes better than seeking direct answers. For example, "Tell me about your cold, Gordon" is preferable to "Do you cough?" The pediatrician should always support the child's *own story*. It should be taken seriously, and confidences should not be violated except in unusual circumstances.

With chronic problems, such as constipation or enuresis, reviewing with patients their knowledge of the complaint is helpful. A child can be asked what was discussed before coming to the physician's office, how the child feels about the visit, how the child's symptoms affect the daily routine and alter the child's lifestyle, and whether the child is able to attend school and carry out all regular activities. Asking children what they think is causing their symptoms, what they are worried about, and why it worries them is also important.

Interviewing the child provides another opportunity to assess parent–child interaction. Many parents cannot let their child speak without addition, interruption, or correction. A school-aged child who clings to a parent and cannot be coaxed to make eye contact with the pediatrician or interact in any way is a concern. As adolescence approaches, parent–child conflicts become more intense. Given the chance, many adolescents will make this distressing situation obvious. Under these circumstances, separate interviews are preferable (see Chapter 119, Interviewing Adolescents). It should be the expectation that teenagers are interviewed alone, for at least a portion of the time.

Typical Day Technique

In many situations, information about a child's typical day can be helpful and informative. Most parents can relate this information readily. In addition to concrete material (eg, sleep patterns, feeding activities), much can be learned about areas of stress and harmony within a family. Parents frequently find difficulty in discussing situations without seeking approval, even if tacit, of their own actions. Parents or caregivers who are confused or unsure of themselves may frequently ask advice on a particular aspect of their child's behavior as it is presented in the description of the child's typical day; however, deferring answers until the entire day has been described is best.

Discussion can begin with an introduction, such as, "To find out more about Kim, I am going to ask you to tell me how she spends a typical day." The physician should then begin by asking what time the child arises and what happens. Some parents will launch into vivid descriptions and will require little direction, whereas others must be encouraged. Details can be elicited by asking some simple questions such as, "What is her mood on awakening?" "Who takes care of her?" and "What does she usually eat for breakfast?" Discussion can include food likes and dislikes, skill in eating, and conduct at the table. The physician can also learn about the child's activities, habits, media use including computer/Internet, social networking, and television viewing practices. The subject of discipline might come up during this discussion, and the parents' beliefs about prohibitions and punishments can be ascertained.

Lunchtime, afternoon rest periods, and activities are reviewed in much the same way. Descriptions of trips to the market or to other stores can provide information about behavior with others and reactions to new experiences. School, daycare, and after-school activities can be explored. What about homework and family chores?

The evening meal is often stressful in many families, and how it proceeds can provide many clues to family dynamics. For example, the physician should find out when the parents arrive home, if the child and/or family eat in front of the TV, whether the child eats with the parents, and, if so, the types of interactions that occur. Information about the events surrounding

preparation for sleep, bedtime rituals, and sleeping patterns are also important.

At the end of such an interview, assessing not only the child's style and temperament but also the family's strengths and weaknesses should be possible. This information is essential for advising parents of children who are having developmental and maturation problems.

QUESTIONNAIRES

In certain instances, parental questionnaires may be used to supplement the history. Some questionnaires may be used as part of a general health appraisal; others are more applicable to a specific problem. Questionnaires are especially helpful for assessing developmental issues, emotional problems, and school problems. The American Academy of Pediatrics (AAP) policy statement on developmental screening includes developmental screening tools that may be incorporated into health maintenance visits. The wise physician will be thoroughly familiar with the questionnaire format and its pitfalls before using it; all such instruments may supply additional information, but all may also be subject to observer bias and should be interpreted accordingly. In addition, the AAP toolkit entitled *Addressing Mental Health Concerns in Primary Care* contains several mental health screening questionnaires.

RECORDING HISTORICAL INFORMATION

Two main goals exist in recording the historical data gained in an interview: documenting the patient's symptoms and medical history, which will help in formulating a diagnosis and therapeutic plan, serve as a legal record of the physician–patient encounter, and provide information for billing purposes; and making a reasonable accounting of the patient's medical status. In doing so, a complaint is transformed into an *illness* or *disease,* and a child becomes a patient. Much can be lost in translation.

The medical record should contain all the medically significant facts of the child's life. The recorded history is a synthesis of material and observations gained during the interview, compiled in a legible, retrievable form.

The present illness must be recorded clearly and concisely. Consistency is paramount, especially when dealing with time. Events must be recorded by using either of these methods: "Dick developed a cough on March 17" or "Dick developed a cough 5 days before our interview on March 23." Using terms such as *Tuesdays* and *Fridays* are difficult to identify 2 weeks after an interview.

Ideally, conditions or concerns should be recorded on a problem list with date of identification and resolution (if possible) included. This allows for quick review and facilitates revisiting ongoing problems.

Data obtained during an interview can be recorded in a variety of ways, such as audio-recording the entire session, a method often used by psychiatrists. Merely noting *Dx-acute otitis media; Rx amoxicillin* × *10 days* on an index card is inappropriate. Electronic Medical Records (EMRs) are essential in providing a high-quality medical home. Records should be legible, and much of the data should be retrievable without having to pore over volumes of paper. This process requires some foresight and planning so that different parts of the history can be separated for later use. Ideally, the historical database should be standard and uniform. However, certain problems change with time (hip clicks, birthmarks) and vary by age and gender (menstrual irregularities), by type of population served, and by geographic locale.

Careful documentation of medications (both prescription and over the counter) currently in use is important; this is often referred to as *medication reconciliation*.

Questionnaires facilitate record keeping and are designed to be age appropriate. They can be filled out by the parent or by a nurse, physician assistant, or other office personnel. However, they also present several drawbacks. First, questions tend to be answered in an idealized way because parents usually have a skewed opinion of their children. Second, all logical sequencing of information gathering is lost, and degrees of concern are not readily expressed. Third, unless the chart is updated frequently by subsequent questionnaires, much of the information soon becomes irrelevant.

The skills involved in gathering and recording a history and communicating compassionately and courteously with patients and their families are difficult to master. Describing a true vignette of the child's condition to professional colleagues and consultants is invaluable. These skills are not innate but rather require work, insight, perseverance, and practice. The work is hard, but the rewards are great.

TOOLS FOR PRACTICE

Engaging Patient and Family

- *1 to 4 Years, From (Part 1): Framingham Safety Survey* (questionnaire), American Academy of Pediatrics (patiented.solutions.aap.org)
- *1 to 4 Years, From (Part 2): Framingham Safety Survey* (questionnaire), American Academy of Pediatrics (patiented.solutions.aap.org)
- *Child Health and Development Inventory System (CHADIS)* (questionnaire), Barbara J. Howard, MD (www.childhealthcare.org)
- *You and Your Pediatrician* (handout), American Academy of Pediatrics (patiented.solutions.aap.org)
- *Your Child's Health Record* (booklet), American Academy of Pediatrics (shop.aap.org)

Medical Decision Support

- *Addressing Mental Health Concerns in Primary Care: A Clinician's Toolkit* (toolkit), American Academy of Pediatrics (shop.aap.org)
- *Bright Futures: Guidelines for Health Supervision of Infants, Children, and Adolescents* (book), American Academy of Pediatrics (shop.aap.org)

Practice Management and Care Coordination

- *EQIPP: Medical Home* (online course), American Academy of Pediatrics (eqipp.aap.org)

- *National Center for Medical Home Implementation* (Web site), American Academy of Pediatrics (www.medicalhomeinfo.org)

AAP POLICY

American Academy of Pediatrics Council on Children With Disabilities, Section on Developmental and Behavioral Pediatrics, Bright Futures Steering Committee, Medical Home Initiatives for Children With Special Needs Project Advisory Committee. Identifying infants and young children with developmental disorders in the medical home: an algorithm for developmental surveillance and screening. *Pediatrics*. 2006;118(1): 405-420. Reaffirmed August 2014 (pediatrics.aappublications.org/content/118/1/405)

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Chapter 14

PEDIATRIC HISTORY: ASSESSING THE SOCIAL ENVIRONMENT

Penelope Knapp, MD

INTRODUCTION

The child's environment may nurture or hinder development from the level of the single cell to the broadest social surround. The pediatrician must be able to appraise environmental threats and assets, particularly in the social environment, to foster the child's healthy development, support resilient adaptation, and maximize social determinants of the child's health.

Figure 14-1 sketches the outline of environmental circles of influence on development. The family is surrounded by the extended family, peers, and other adults with direct influence on the child's experiences.

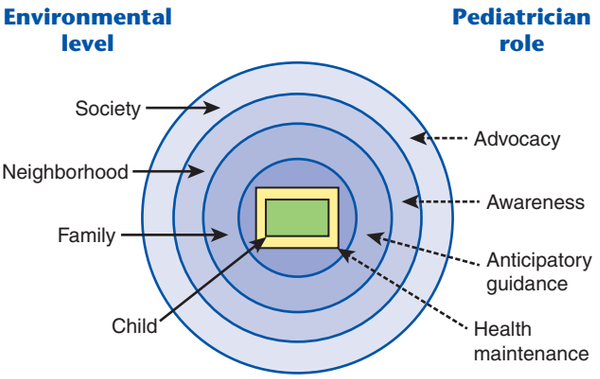


Figure 14-1 Environmental circles of influence on development.

They are in turn influenced by the neighborhood, including school, which lies within a broader social environment that impinges on the child's world.

Broadly, the social environment may be considered as intrafamilial or extrafamilial. The intrafamilial social environment is the personal world of relationships with intimates; the extrafamilial social environment is the world in which the family lives and raises the child. The external environment influences how parents' and children's intimate relationships flourish or falter inside the family environment. The pediatrician's capacity to optimize children's health goes beyond well child care and treatment of illness to inquiring about the child's social environment in order to provide preventive interventions.

Biologic Needs and Vulnerabilities

Social development has both a biologic basis and neurobiologic consequences. Normative theories of child development describe the progression from the newborn's complete dependence on parents through the acquisition of strengths, knowledge, and skills, and pursuit of independence and relationships outside the family during childhood and adolescence. This progression, propelled by physical and neurologic maturation, is well known to the pediatrician, and the pediatrician's role in helping the parent to understand and facilitate the child's development has been well established. To optimize biologically driven maturation, a fuller understanding of the critical influence of the child's interpersonal and social environment is also necessary, because psychological and social development is necessarily interpersonal and mediated by experience. The pediatrician should routinely and systematically assess the parents' and caregivers' understanding of the child's developmental capacity.

Knowledge of genetic influences on health and development is increasing rapidly. In parallel, awareness of genetic influences on social-emotional development and environmental influences on genetic expression is growing. Shared and nonshared idiosyncratic environmental factors contribute to individual differences in siblings in the same family, as shown by studies of adoptive and biologically related same-sex sibling pairs from the Sibling Interaction and Behavior Study

(SIBS), although genetic influences continue to be expressed even into adolescence. The importance of early and middle childhood is a new emphasis for Healthy People 2020, in recognition that positive social development has a biologic effect.

Relationships will determine how any child develops as a social being, beginning with the earliest reciprocal interactions of the infant with the parent, which influence gene expression and shape or reinforce neural architecture. Brain development proceeds according to the quality of relationships with siblings, teachers, and peers.

The younger the child, the more vulnerable he or she will be to family mental health problems or violence. Because the quality of the child's relationship to parents or caregivers will influence the child's ongoing physical and emotional response to stress, these relationships must be supported. The pediatrician's encouragement of strong early relationships is a powerful preventive intervention, not only during infancy, but throughout childhood and adolescence as the child and parent develop.

The pediatrician should assess the parent–child relationship, the child's social-emotional and developmental status, the degree to which the parent can protect the child from stress and injuries, and whether the parents can provide predictable routines to establish the child's sense of security. Early recognition and screening for emerging mental health problems has been facilitated by the work of the American Academy of Pediatrics (AAP) Task Force on Mental Health, including a summary of mental health screening and assessment tools for primary care (see Tools for Practice at the end of this chapter).

Environmental Threats to Family's Functioning

Environmental threats to the developing child may begin in utero. Exposure to toxic environmental agents such as lead, allergens, and pesticides, is ubiquitous, but disproportionately affect minority, vulnerable, and underserved populations. In addition, secondhand smoke exposure is higher among children at 185% of the Federal Poverty level and below. Almost all parents strive to do their best for their children, but many work against daunting odds. Children and single mothers are increasingly overrepresented among the poor. Children comprise 43% of people in poverty, and 70% of children who live with a single parent, usually their mother, live in low-income families (defined as those whose household income is less than twice the federal poverty level), as compared to 48% of children with married parents. The likelihood that a child is growing up in poverty is higher if the family lies in a poor area (identifiable by ZIP code) and if the parents have less education, are recent immigrants, and have part-time or no employment. Direct effects of material impoverishment, such as inadequate nutrition leading to developmental delay, are compounded by the increased likelihood that poor children will be exposed to other hazards such as substandard housing, lead poisoning, parental psychological distress, inadequate child care arrangements, or neglect and abuse.

Children of color are disproportionately affected: in 2011, children in single-parent households varied by ethnicity; 67% were in black non-Hispanic families, 53% in Native American families, 47% in Hispanic families, 25% in white non-Hispanic families, and 17% in Asian American and Pacific Islander families. It follows that very young children of color are overrepresented in child welfare, comprise the largest proportion expelled from early care and learning settings, and are likelier to require specialty mental health care. They are also likelier to be victims of abuse, sexual abuse, or neglect in the home or neighborhood, and at best are more subject to experience factors placing them at risk for poor behavioral and social-emotional development.

Furthermore, it is more difficult for low-income parents without social supports to meet the basic needs of very young children and those with special health care needs. Parents of any economic level who have experienced adverse child experiences (ACEs) in early years may be at risk for poor or maladaptive parenting, may have diminished capacity to respond to stress in a healthy way, and also have a higher risk of health, mental health, or substance abuse problems. In addition, if a parent is working multiple jobs or is too depressed, tired, or detached to engage with children in challenging settings, they may resort to allowing excessive screen time or substituting media for parent–child interaction. The pediatrician should inquire about the family's ability to provide adequate nutrition, the safety of their housing, whether the parents are distressed, whether child care is of adequate quality, and whether there is neglect or abuse.

THE FAMILY ENVIRONMENT: RELATIONSHIPS AND CULTURE FOR THE DEVELOPING CHILD INSIDE THE FAMILY

Family Composition

The child's neurologic maturation, psychological growth, and development of social self are shaped by his or her intimate relationships. It is helpful to know how many people are in the child's family and how they influence the social environment. Optimal child development is linked to parent and family characteristics. Children whose parents are more educated, have higher incomes, have lower psychological distress, and provide emotionally supportive and cognitively rich environments show more cognitive, language, and social competence and more harmonious relationships with their parents. Grandparents may have a large direct role in child rearing, especially if the parent is an adolescent; but they are also involved indirectly, by transmitting family culture. Increasing numbers of same-gender parents raise children, but there is no causal relationship between parental sexual orientation and the child's healthy emotional development.

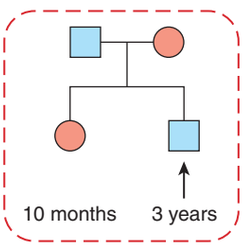
The family member bringing the child for pediatric care may be a grandparent or step-parent. Grandparents may be the child's primary caregivers because the extended family lives under a single roof, or for reasons involving tragedy, illness, substance abuse,

incarceration, deportation, or young age or military deployment of the biologic parent. Grandparents, undertaking the vigorous tasks involved with raising young children, may themselves have physical limitations or health problems. They may also be contending with role confusion, financial difficulties, or involvement in problematic custody disputes, which strain their capacity to provide a secure relationship base. Step-parents face a challenge to develop secure and robust attachments with the children they have undertaken to help raise—children who have adapted to earlier troubling experiences, whose loyalties may be unsettled, and whose emotions may be difficult for them or their parents to endure. Children in stepfamilies experience higher rates of unintentional injuries, and overall do not do better than children raised by single parents. However, step-parents may also enrich a child's upbringing economically and emotionally, offering the presence of an additional loving figure. Pediatricians should be aware of strengths and risks in the family composition.

A social genogram, similar to those used for identifying heritable diseases, but also depicting the child's relationships and who is in the home, is a useful tool for understanding the child's social world. Genogram software is available that describes standard symbols, including those for medical conditions and for describing social relationships. See Figure 14-2 for a simple example.

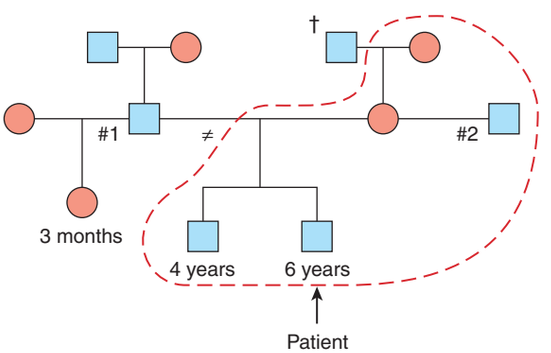
Example 1

The patient, a 3-year-old child, is the oldest of 2, living with both parents.



Example 2

The patient, a 5-year-old child, is the oldest of 2 boys, living with mother and stepfather. The child's father has remarried and has an infant daughter. The maternal grandmother lives in the home; the maternal grandfather is deceased.



, male; , female; #, number of partner(s);

, persons living in household; ≠, divorced; †, deceased.

Figure 14-2 Example social genograms.

Attachment

Attachment theory provides an important lens for viewing social development. Children of any age actively adapt to their relationship environment, and within the constellation of that interpersonal environment, they develop self-regulation and automatic expectations about others. Original studies of attachment indicate that most infants and toddlers have secure attachments with their primary caregiver. Children with insecure attachment styles fall into 3 groups, termed insecure/avoidant, resistant/ambivalent, and disorganized/disoriented. Attachment types are specific between an infant and a particular caregiver, are predictable from normal caregiving behavior in the first year of life, and remain stable to at least 6 years of age. Sensitive, responsive care leads to secure attachment. Rejecting caregiving leads to insecure/avoidant attachment. Inconsistent caregiving leads to resistant/ambivalent attachment.

If the constellation of intimate parent–child interactions is troubled, or disturbed enough to be characterized as attachment disorder, the child is at high risk for developing self-perpetuating troubled patterns of interactions with other children and adults. The pediatrician must recognize disordered attachment, not only because the child's development is contingent upon reciprocal interactions in an attached relationship, but also because without early intervention, disordered attachment may jeopardize or distort later close relationships. The *Diagnostic and Statistical Manual of Mental Disorders*, fifth edition (*DSM-5*) recognizes 2 types of attachment disorders: reactive attachment disorder and disinhibited social engagement; these have previously been described as nonattachment and indiscriminate sociability. This pattern of shallow, friendly, engaging behavior may result from cycling through multiple caretakers before removal from the parent, and multiple foster placements thereafter. Reactive attachment disorder may resemble internalizing disorders, with a lack of or incompletely formed preferred attachments to caregiving adults and a dampened expression of joy or happiness. Disinhibited social engagement disorder more closely resembles attention-deficit/hyperactivity disorder and may occur in children who do not lack attachments or who have established or even secure attachments. Children with disordered attachment may exhibit symptoms ranging from withdrawn behavior to angry, aggressive behavior.

Children with both patterns of attachment disorder are very challenging to parent, as they have difficulties with self-regulation along with disruptive or disturbing behavior, and they cannot return the love and trust that their parents try to give them, leaving the parents feeling ineffective and distressed.

Measures of attachment are available for both adults and children. If the pediatrician is concerned about the quality of the child–parent attachment, a

fuller history or use of a screening tool is indicated, followed by referral to a mental health professional for further assessment.

Another lens through which to view the infant's earliest relationships is the transactional model, which provides a comprehensive view of the interaction between nature and nurture, focusing on relations between the genotype (ie, the individual's biologic organization), the phenotype (ie, the individual's personal organization), and the environtype (ie, the organization of experience). The child's behavior is seen as a product of transactions among the genotype, phenotype, and environtype. The transactional model provides a framework for early intervention that can emphasize, depending on the nature of the relationship problem, remediation of the child's behavior, redefinition of the parents' interpretation of the child's behavior, or re-education of the parents to change their behavior to the child.

Parenting Style

The culture within the family will shape the relationship and learning environment for the child. Families have individually distinct beliefs, rituals, and routines related to health and discipline. Baumrind's classical descripton of 4 parenting styles is widely used: Authoritative parents are comfortably consistent in providing limits and guidance to shape children's behavior and support their learning; they both demand that children adhere to developmentally appropriate clear standards and respond warmly to children's needs. Authoritarian parents, by contrast, demand but do not respond; they impose noncontingent or punitive discipline that children may experience as arbitrary, unfair or confusing. Permissive parents are responsive but not demanding; these parents fail to provide their children with consistent rules or discipline, so the child struggles with their own impulses without predictable controls. Uninvolved parents, also termed rejecting-neglecting parents, neither demanding nor responsive, do not provide emotional scaffolding to help children understand the effects of their emotions and feelings.

Children depend on their parents' control of the family emotional environment and on their engagement and stimulation for basic learning. This has measurable effects upon learning: young children whose parents have low responsiveness to their developmental activities have delayed vocabulary. Numerous instruments are available for assessing parenting style. In the Suggested Readings at the end of this chapter, see Johnson et al for a review, and Kemper & Kelleher for approaches to family psychosocial screening.

The pediatrician should observe parenting style in the office and ask about parenting stresses and challenges, and if concerns are noted, consider referral to a mental health professional for fuller assessment.

Parental Mental Health: Maternal Depression, Intimate Partner Violence, and Substance Abuse

For infants and young children, the environment is created and embodied by the parents, particularly the mother. Parental mental illness powerfully affects the emotional and possibly the physical environment in the home. The 12-month prevalence of mental illness in adults in the United States is estimated at 32.4% (National Comorbidity Survey replication, www.hcp.med.harvard.edu/ncs/index.php), and Nicholson and colleagues note that two-thirds of these individuals are parents. A child whose parent has a mental illness is more likely to have developmental delay, difficulty regulating emotions, and/or problems with relationships. One-fifth of children in the general population have a psychiatric diagnosis, but 30% to 50% of children with mentally ill parents have a psychiatric diagnosis, so recognition of parental mental disorder is necessary to prevent or minimize childhood psychiatric disorders.

Depression has a prevalence of 16.6% in the population. According to the AAP, 400,000 infants are born each year to mothers who are depressed. Despite easy availability of depression screening, such as the Edinburgh Postnatal Depression Scale, a 10-item screening tool available in the public domain, depression in most mothers is either unidentified or untreated. Only about 10% of women experiencing postpartum depression discuss their symptoms with their physician. Because babies are wholly dependent on a caregiving adult for survival, they are therefore at greatest risk for abuse, neglect, and inadequate medical care. Babies' earliest reciprocal experiences shape the developing brain. Many depressed mothers work hard to meet their children's needs, but some infants of depressed mothers are at risk for developmental delay, impaired social interaction, attachment problems, behavior problems, and later problems with cognitive and social-emotional development.

Growing up in the environment created by a depressed mother may also affect children before and beyond infancy. Riley and colleagues, evaluating combined reports (mother, father, teacher) about children whose mothers were depressed, found that their adaptive skills were significantly poorer than those of sociodemographically similar children whose mothers were not depressed. Parents reported more emotional and behavioral problems among these children. Measured family stressors did not mediate the association with children's psychosocial problems, but the quality of mothers' parenting did.

Maternal depression is a cumulative risk factor because it sets in motion multiple risk processes. This process has been described and explained by the "launch-and-grow" cascade model through which the earlier risk factor, exposure to maternal depression before age 12, was demonstrated to predict other risk processes—stress, altered family relationships, and reduced self-worth—that set the course for children to develop depressive symptoms over time.

It is difficult to estimate the prevalence of intimate partner violence (IPV) between parents and children's witnessing domestic violence (DV) among others in the home, but its powerful toxicity to the child's emotional environment is obvious. Families with physical abuse between parents are likelier to be families with child maltreatment, and psychological abuse between parents is also strongly related to maltreatment of children. Even when only the husband perpetrates physical abuse toward the wife, the odds of child

neglect were found to be 5.29 times as great as in families with no psychological abuse. A pediatrician who uncovers a situation involving violence in the home should question whether the child has witnessed it, if the child's safety is jeopardized, and if the mother feels safe or has a plan if she does not feel safe.

Childhood exposure to IPV is a toxic stress associated with poor social-emotional child health outcomes and significantly more externalizing, internalizing, and total behavior problems. Both the age at which a child is first exposed to violence at home and the amount of violence the child witnesses in their lifetime have been found to be significantly related to behavioral problems. Cumulative violence exposure has been shown to have a greater effect, and also to mediate the relationship between early exposure and later externalizing behavior problems. This may include excessive exposure to violence through media. In addition, McFarlane and colleagues found children aged 6 to 18 years to be at greatest risk following psychological abuse in the home.

Thus, exposure to physical and psychological abuse between parents is an example of environmental stress that is both formative at an early age and cumulative during childhood. This presents an opportunity for prevention: identifying and intervening in families with abused mothers may prevent the development of problems for their children, as well as ensure the safety and well-being of the child and mother.

The prevalence of substance and alcohol abuse among adults who are parenting children is also difficult to estimate, but the likelihood of child maltreatment leading to out-of-home placement is higher in these families. From the child's perspective, the parent who is using substances inevitably provides a fluctuating interpersonal environment, depending on whether they are under the influence or experiencing withdrawal.

Children exposed to maternal substance abuse suffer both nonspecific risk and, in the case of alcohol exposure leading to fetal alcohol spectrum disorder, specific neurodevelopmental harm. Parental substance abuse is part of a cluster of risks: it is often associated with a chaotic, harsh, and stressed environment, exposure to interpersonal violence, and dysregulating experiences that prevent minimally adequate or consistent care for the child. Also, alcohol and substance abuse are related to parental depression or trauma, so even if the situation does not lead to active maltreatment, the home environment poses a threat to the child's adjustment.

The child is therefore intermittently or continuously deprived of a safe and solid relationship with a special adult who puts the child's needs first and is emotionally available to respond in all the ways that allow the child to build neuronal connections in an organized way within a secure attachment. Such kinds of toxic early experiences present an unfortunate "natural" experiment. Because normal language and cognitive development are contingent on environmental stimulation through earliest relationships, most young children coming into foster care show speech and language delays, and almost half show cognitive delays. However, these risks do not apply exclusively to foster children. Early recognition of parental problems is an important preventive measure. The pediatrician should observe for or ask about maternal depression, interpersonal or domestic violence, and substance use. Screening tools may be useful.

Discipline

Child rearing is challenging. The pediatrician will support positive parenting strategies; nonetheless, parents must at times set limits and provide consequences to guide their child to safe and prosocial behaviors. In what ways and how often parents set limits and provide discipline for their children depends on characteristics of the parents, the behaviors or predilections of the child, and the social context. Among these, parental characteristics such as warmth, protectiveness, or authoritarianism may be the most influential in determining the type of discipline used.

Limit setting and discipline are necessary elements of rearing most children. Each parent and each family develops a style for these, with a range from nonverbal demonstration of disapproval to scolding, to spanking. The AAP recommends against corporal punishment, yet it is endorsed or used at some times by most parents in the United States. Frequent corporal punishment is associated with other parenting risk factors, including whether parents considered abortion and whether there is neglect, physical and psychological maltreatment, IPV, maternal stress, substance use, and depression. In a large birth cohort study of children in 20 large US cities, frequent use of corporal punishment (defined as spanking more than twice in a month) with 3-year-old children was found to be associated with higher levels of child aggression when the child was 5 years of age, even controlling for key demographic features and potential confounding factors noted earlier.

The style of discipline of children is influenced by culture. In a study of low-income white, African American, and Mexican American families of toddlers, both spanking and verbal punishment were found to vary by maternal race/ethnicity. The interaction between harsh discipline and child temperament and behavior is complex and iterative, but overall, punishment does not improve behavior. Specifically, child fussiness at age 1 year predicted verbal punishment and spanking at ages 1, 2, and 3 years, but neither aggressive behavior problems in the child nor the child's development scores on a standardized measure predicted later spanking or verbal punishment. On the other hand, spanking at age 1 year predicted higher child aggressive behavior at age 2 years and lower scores at age 3 years. The effects of spanking and verbal punishment were moderated in some cases by mothers' race and ethnicity and her emotional responsiveness.

Mothers who did not endorse physical discipline, and who nonetheless spanked their children, were found likelier to be suffering from maternal distress, and in these families there was a stronger relationship between frequency of spanking and depressive symptoms reported by their children. The pediatrician should ask about parents' views on discipline, specifically for what behaviors, how, and how often they discipline their children.

Family Disruption, Dissolution, and Variation: Cohabitation, Divorce, Blended Families

When the family shatters or scatters, the child is threatened and challenged to adapt. Disputes and tension may precede family disruption, and children, even very young ones, are affected.

About 50% of marriages end in divorce, and about half of school-age children spend time living with a single parent or in a stepfamily. Divorce, even when both parents love their child, presents a challenge to children's adjustment. Troubled and contentious marriage is a frightening emotional environment for the child, and one-third of divorced parents continue to contest child custody and visitation arrangements. Boys are more vulnerable to developing adjustment problems in such emotional environments, and girls are more vulnerable to depression if their mothers are depressed. Added to the effect on the emotional environment within the family is the fact that following divorce, most children spend most of their time with their mother, who almost always suffers reduction of economic stability.

Economic uncertainty may influence whether cohabiting couples raising children are able to maintain stability. Mother–child files from the National Longitudinal Survey of Youth indicate that in 1997 about one-fourth of children lived for some time during childhood in a family headed by a cohabiting couple; in 2011, 7% of children did. Subsequent, sometimes rapid, changes in family status may occur, posing adjustment challenges or threat of loss of important relationships for the child. The pediatrician should ask about the economic effect and time course of family changes and help the parent to understand and alleviate their effects on the child, considering the child's developmental level.

Children in Foster or Kinship Care

Half a million children in the United States are in the child welfare system, having been removed from their parents' care because of neglect or maltreatment. The adults parenting children in out-of-home placement may be extended family members, foster parents, or residential care providers. Removal is typically preceded by toxic or troubled attachments, so the separation from the parent or parents is a loss for an already stressed child, as described by Szilagyi. The pediatrician caring for a child in foster or dependent care should expect complex issues. Knowledge of foster care agencies and familiarity with consent and confidentiality issues is necessary. Often, the child's full medical and developmental record is difficult to obtain, yet the pediatrician must take on the responsibility for health care case management and for promoting regular comprehensive preventive health care. The pediatric medical home should ensure that these children have access to all necessary services, and should maintain communication with their social services agency. Optimizing the physical, emotional, developmental, and mental health status of children in dependent care requires extra attention to screening and documentation. Guidelines found in the second edition of the AAP publication *Fostering Health: Health Care for Children and Adolescents in Foster Care* provide further detail. (See also Chapter 72, Children in Foster or Kinship Care.)

Younger children and infants in out-of-home placement are most vulnerable. In 2006, 169,500 children ages 5 and younger were in foster care (34% of the 510,000 children in the child welfare system). In the United States, maltreatment presents the highest risk of morbidity and mortality for infants and toddlers. These young children have usually suffered experiences that put the development of robust foundations for relationships at grave risk. Early recognition will enable early intervention, but often the pediatrician is appealed to for pharmacologic intervention to reduce children's troubled and troubling behaviors. However, evidence-based interventions to support foster parents can help avert the socially destructive process of multiple foster home placements for children with troubled attachments.

Child Protective Services is a necessary ally for the primary care physician, who is mandated to report abuse or neglect. As a mandated reporter of abuse, the pediatrician must recognize the threshold for reporting, but also as a physician who knows the child in the medical home, the pediatrician will put together the child's story to understand the effect of timing of stress in relation to the child's developmental stage.

THE FAMILY'S ENVIRONMENT AND CULTURE: FACTORS OUTSIDE THE FAMILY

Risks, Assets, Resilience

When the environment around the family is strained or threatening, parents' capacity to buffer stress for their children may suffer. Environmental risk rises as income and socioeconomic status fall. A salient fact of poverty is exposure to multiple environmental risk factors that threaten health and well-being for adults and children. Quality health care, child care, and education are harder to access. The neighborhood may lack resources or be unsafe. It may be more difficult for poor families to supervise their children and protect them from the physical and social dangers in their environment.

Risk factors (abuse, neglect, witnessing violence in the home, family discord or divorce, parents with poor health habits, unsafe schools, and unsafe neighborhoods) may be counterbalanced with assets (stable relationships with caring adults, anchor in a faith or spiritual belief or community, involvement in school, available recreational opportunities). Children continuously adapt, and their adaptive repertoire increases with age if they have a solid base upon which to build. It is beyond the power of the pediatrician to prevent the family's misfortune, but noting potential risk factors is important, and the more important question is how the family and child are coping.

Resilience is defined as good adaptation in relation to risk. No matter how resilient the child, more risk is a negative factor. It has long been known that cumulative risk factors increase the threat to healthy development. For example, children with numerous environmental risks, such as having a mother whose capacities are compromised, or living in a chaotic or violent family environment or in poverty, are more than 24 times likelier to have IQs below 85 than are low-risk children.

US Department of Education data show that young children living with multiple risk factors are less likely to achieve benchmarks for early school success. Young children from low-income neighborhoods have a higher incidence of behavioral problems with a negative effect on their development than children growing up in moderate-income or wealthier areas. Children of mothers with mental health conditions or substance abuse problems, or those exposed to domestic violence, are 2 to 3 times more likely to manifest aggression (19% vs 7%), anxiety and depression (27% vs 9%), and hyperactivity (19% vs 7%).

In evaluating the child's environmental risks, the pediatrician also weighs the child's resilience. Supporting parents' coping will directly benefit the child. Recognizing assets and areas of strength and helping parents to build children's resilience will counter the effect of environmental stress on the child.

Unemployment, Underemployment, Poverty, Homelessness

Job loss, with associated financial strain and hardship, affects families greatly and is more common during economic recession. Stressors in the aftermath of job loss include depression and decline in the quality of the parents' relationship. For 2-parent families, both the parent seeking employment and his or her partner may experience depression and reduced relationship satisfaction. The economic environment may affect the child, even if parents are capable and affectionate. Increasing numbers of American households, including 16.7 million children, experienced food insecurity in 2011. Unemployment, rather than poverty, is the strongest predictor of food insecurity.

Households headed by women with limited education and those with teen births are especially vulnerable to economic catastrophe. In a labor market that has shifted away from manufacturing jobs, options for work for women with limited education and job skills are often limited to service-sector jobs with low pay, inadequate benefits, and inflexible hours. This presents a relentless challenge for single mothers, who bear sole responsibility for wage earning, child care, and homemaking. In addition to these pressures, they also must negotiate eligibility for Temporary Assistance to Needy Families (TANF) and Supplemental Nutrition Assistance Program (SNAP, also known as food stamps), and face long waiting lists for affordable housing.

Single mothers in low-wage jobs have been found to exhibit increased symptoms of depression, which directly and negatively affect their psychological functioning and the quality of their parenting, with measurable effects on their children's behavioral and academic outcomes. This is compensated for if mothers have higher educational attainment and capacity to provide emotional support for their children.

Extreme poverty, defined as household income at or less than 50% of the Federal Poverty Level (FPL), is the strongest predictor of family homelessness. Of the 2.3 to 3.5 million Americans who are homeless each year, 34% are families. The number of homeless children is increasing: currently 1.5 million children, or 1 child in 50, experience homelessness. Two-thirds of homeless children worry they will not have enough to eat, and overall they are twice as likely as middle-class children to actually experience hunger and to have moderate to severe health problems, both acute and chronic.

Very low birth weight, poor general health, malnutrition, exposure to lead and other toxins, maltreatment, and victimization are all endemic correlates of poverty. Thus, at a biologic level, poverty interferes with children's capacity to benefit from education. At a social level, the education available to the child may be compromised. In low-income districts, schools may be inadequately funded and their academic resources limited. Child care is likely to be of lower quality, schooling poorer, and some administrators and teachers may have low expectations of their students. Scarcity of books in the home may further impede children's cognitive development. Lack of parental engagement, reading, and family play, and too much screen time can do so as well.

Educational readiness requires good child mental health, which in turn depends upon parents' mental health. Compromised parental mental health, particularly maternal distress and depression, is more common in low-income families. This may disrupt the parent-child relationship upon which a child's social, emotional, and cognitive development is founded. Not surprisingly, children in low-income neighborhoods, with poor housing conditions, high unemployment, and high crime rates, have higher rates of behavior problems that affect their school readiness and performance.

For homeless children, disruption of schooling means they are twice as likely to be expelled or suspended from school, or to repeat a grade. Their estimated graduation rate from high school is below 25%, and at the end of high school, few are proficient in reading and math. It is important to recognize that a child's developmental or mental health "symptoms" may be reasonable adaptations to the stresses of his emotional environment, and that these should be understood and addressed before a psychiatric diagnosis is made.

Parental Employment: The Working Mother

Increasingly, mothers must work for financial reasons. Pediatricians can support working parents by assessing how they balance demands of work and home, determining whether they have adequate child care options, and providing advice about finding quality child care. This may lessen the extent to which parents' work may draw away their available energy and the emotional resources needed for parenting. One-half of women with infants and 64% of women with children are in the workforce, most in full-time jobs. Although overall, research does not support the concern that family relationships, attachment to children, or children's development is harmed by the fact of a mother's work alone, some fatigue and strain inevitably accompanies working, and if the quality of child care is inadequate, children's developmental opportunities will be compromised.

The question of whether children suffer if their mothers work full time has been much debated. The NICHD

Study of Early Child Care and Youth Development showed that in a sample of more than 1,000 demographically and ethnically diverse children, the average child spent 27 hours a week over the first 4½ years of life in nonmaternal care. During children's first 2 years of life, most child care took place in family homes with relatives or in child care homes. As children aged, more were in center-based (formal) care. According to the NICHD report, family and parenting experiences were as important to the well-being of children who had extensive child care experience as they were for children with little or no child care experience.

The pediatrician should ask about hours of parental work, strain associated with work, and how the parent and child are dealing with it, particularly if the parent resorts to letting the child have screen exposure to occupy the time required to prepare meals and manage household chores.

Child Care

The child's experiences outside the home open opportunities for social-emotional development. Children who attend preschool may be more ready to learn when they enter school, but the proportion of children enrolled in preschool and the quality of care they receive differs according to ethnicity and race. Black and Hispanic children are more likely than white children to participate in Head Start programs. Hispanic children are less likely and black children are more likely to attend preschool than are white children, but the quality of care received may be lower for black children.

Quality of child care is an important factor for preschool children. High-quality care attenuates negative effects of economic disadvantage on children's early academic trajectory. For children whose mothers had low levels of education, formal child care led to higher receptive vocabulary, reading and math achievement scores, and school readiness than for those cared for by their parents. Although children experiencing higher-quality child care have better language and cognitive development, and are more cooperative than those in low-quality care, long hours in child care, even of high quality, may take a toll. Children with higher combined numbers of hours in nonmaternal care showed relatively more behavior problems in both child care and kindergarten classrooms than did those who had spent fewer hours away from their mothers. Cognitive and language development was found to be somewhat better for children who attended child care centers, but also they showed more behavior problems in child care and kindergarten classrooms than children who were placed in other nonmaternal child care arrangements.

Child care is an early watershed for children with social and emotional problems, and may either add to the child's positive experience or exacerbate risks. Young children in preschool have 3 times the expulsion rate of children and youth in K-12 grades. Expulsion rates of 4-year-olds are 50% higher than for 3-year-olds, and boys are 4 times likelier to be expelled than girls.

The pediatrician should ask if the child care setting is formal or informal, how confident the parent feels in the child care providers, how many hours per week the child spends there, and what happens during the child's day (eg, if much of the time is spent in front of a television set).

School

School-age children spend most of their days in an educational environment that may be safe, supportive, and stimulating or that may threaten them, leave them feeling confused or unsure, and fail to engage their minds. Racial and ethnic gaps in school readiness carry over from early childhood care and education to affect the child's opportunities in school. The parent and the pediatrician need to know about the quality and environment of the school and whether the school has academic and social resources to optimize students' learning. It is important for the pediatrician to learn about the child's school as well as to know how the child experiences school. Does the child feel that the teacher and the other children like him or her? Does the child feel able to do the work? Has he or she experienced bullying?

School administrators and staff should be aware of bullying if it occurs, because 85% of the time other children witness bullying. Bullying is not a random event; individual child characteristics and family factors may be predictive. Children who are bullied show signs of distress and problems adjusting; these may be the cause or the effect of being bullied. Bullying persists and can be stable across ages, and the mental health effects of childhood bullying may persist until late adolescence. It is associated with internalizing mental health symptoms including self-harm, as well as violent behavior and trauma-associated psychotic symptoms. The pediatrician should inquire about the quality of school and the child's experience, including bullying and, especially for adolescents, cyberbullying.

The Neighborhood

The child's neighborhood provides contact with other adults and children, as well as opportunities for play, learning, and community experiences. Impoverished and unsafe neighborhoods obviously limit those experiences. Disorganized neighborhoods with large numbers of youth in trouble pose actual danger. Children growing up in dangerous neighborhoods may be denied opportunities for exploration because their parents seek to protect them from harm. The same factors that jeopardize children's readiness for school or success in school may pose risk for gang activity in neighborhoods. Disorganized neighborhoods with large numbers of children who have poor relationships with their parents, who have a low attachment to school, and who have associations among peers involved in delinquent activities such as violence and drug use, are neighborhoods vulnerable to gang presence. According to a recent biennial School Crime Supplement to the Bureau of Justice Statistics (BJS) National Crime Victimization Survey, the proportion of urban students reporting gangs present at school (24%) is increasing.

This may not be a problem only for inner-city neighborhoods. According to the same BJS Survey, an increasing percentage of suburban and rural students ages 12 to 18 years report that gangs were present at their school during the previous 6 months. The rise in

gang activity at schools is partly because gangs use the venues of middle schools and high schools for recruitment and drug distribution. Gangs may direct their members who have dropped out of school to reenroll in order to recruit new members and sell drugs.

The pediatrician should be informed of or inquire about the quality of the neighborhood and how parents cope with potential dangers. Bright Futures provides information and resources on promoting community relationships. It also guides pediatricians to resources for vulnerable families who are recent immigrants or who have limited English proficiency.

Military Deployment; Military Culture

Approximately 1.76 million children and youth grow up in military families, and they are younger than the national average: in the overall population 66% of children are under age 11, but in families on active duty, 78% of children are under 11. Frequent moves, multiple deployments, and injury/loss of a parent are facts of military life that inflict psychological stress on children and their parents. Stress related to deployment is associated with increased incidence of marital problems (44% among active duty and 39% among reserve), and military families' rates of mental health disorders and trauma are higher than national rates. In families of enlisted Army soldiers, child maltreatment was found to be 42% higher during deployment than during nondeployment.

In particular, the wartime deployment of a parent is highly stressful for a child. One-fourth of children with deployed parents experience depression; one-fifth exhibit academic problems. Parents remaining behind experience stress, of which even young children are aware. Children's difficulties are proportional to the mental health difficulties and coping problems of the parent; their mental health symptoms include externalizing and internalizing problems. For veteran spouses returning with PTSD, interpersonal violence rates are higher, and their partners experience higher caregiver burden and manifest poorer psychological adjustment. Mental health resources available to military families, including reserve and National Guard families, are often insufficient to meet families' needs.

Pediatricians who care for patients in military families, whether active duty, veteran, or reserve, or who practice in groups that contract with programs serving veterans or reserve families, will need to recognize and respond to child and family stress associated with the military environment. (See also Chapter 77, Children in Military Families.)

The Virtual Environment: Media, Video Games, and Television

The AAP recommends no television for children under 2 years of age and limiting exposure to screens, including TV, smart phones, and video consoles, to 2 hours a day for older children. Regardless of the home environment and the school and neighborhood environment, children may be exposed to the virtual environment of media by exposure to television, video games, and the Internet. The positive or negative effects on the child depend on the timing, quantity, and quality of this exposure.

For very young children, even apparently benign exposure presents some risk. For infants 8 to 16 months old, each hour per day of viewing baby DVDs and videos was associated with a 16.99 point decrease in MacArthur-Bates Communicative Development Inventory, whereas among toddlers 17 to 24 months old, no statistically significant association was seen. For very young children whose language development is progressing most rapidly, exposure to baby DVDs and videos cannot substitute for reciprocal language interaction with adults and other children.

For older children, screen media exposure (television and video games) has been found to be significantly associated with teacher-reported attention problems, controlling for gender and earlier attention problems. This finding held across media type (TV, video games) and age (middle childhood to early adult). Over time, the negative effects are cumulative: every additional hour of television exposure at 29 months corresponded to a 7% decrease in classroom engagement, a 6% decrease in math achievement, a 10% increase in victimization by classmates, a 13% decrease in time spent engaging in weekend physical activity, a 9% decrease in activities involving physical effort, higher (9%) consumption of soft drinks and snacks (10%), and a 5% increase in body mass index.

For children and adolescents with good adjustment, online activity may be an asset. In a longitudinal sample of youth, the patterns of their peer relationships, the quality of their friendships, and their behavioral adjustment predicted the qualities of both interaction and problem behavior on their social networking Websites at ages 20 to 22 years. Thus, consistent with developmental theory, there is cross-situational continuity in youths' social behaviors, and this extends to the online domain. However, risk of victimization by pedophiles via online contact is also present, and may be higher for youth whose family support and adjustment are compromised.

The online environment also enables cyberbullying. In a large, diverse sample of urban middle- and high-school students, half (49.5%) indicated they had been bullied online, and 33.7% reported that they had bullied others online. Most bullying was by and toward friends, and generally youngsters did not tell anyone about the bullying. After being bullied online, they reported feeling sad, angry, and depressed. Those who bullied others online reported that they did so to feel popular, powerful, or funny, but many reported feeling guilty afterward.

The pediatrician should discuss with the family and the child what type of media exposure the child has, and how it influences him or her. Specific questions about media use shoud explore whether the media diet is healthy, and whether the child or adolescent turns to media because of loneliness, lack of interaction in the home, or difficulties with peer relationships. (See also Chapter 43, Healthy Use of Media.)

CONCLUSION

The developing child is constantly trying to balance the physical environment, the intimate relationships of the family, and the direct and virtual social environment. To interview parents about the list of

environmental and risk factors presented in this chapter may seem daunting, because the focus of the pediatrician is the child patient, and the pediatrician's capacity to address environmental risk is necessarily limited. Thus, it is crucial to work collaboratively with the family who embody the child's intimate personal environment, and who live in a larger neighborhood and social environment that affects their capacity to optimize their child's experiences. The general area of anticipatory guidance, safety, and health promotion is a broad topic well covered by Bright Futures and in other chapters in this textbook. The AAP Task Force on Mental Health and American Academy of Child and Adolescent Psychiatry Mental Health Task Force have developed guidelines for recognizing mental health problems in children and guiding them or their troubled family members to specialty services.

This chapter presents a recent literature review of the effects of the environment on the child. It links this information to developmental and psychological effects on the child, and offers guides to questioning and intervening. Table 14-1 summarizes areas for interviewing the parent. The interview about the social environment will empower parents and help them to address risks and optimize their child's environment.

Table 14-1 Domains of Inquiry About Social-Emotional Environment

	FACTOR IN SOCIAL-EMOTIONAL ENVIRONMENT	EVALUATE
Overall factors influencing biologic basis of social-emotional development	Developmental progression	*Parent's understanding of child's developmental capacity.*
	Quality of mother-child relationship	*Parent–child relationship: can parent protect child from stress and injuries and provide predictable, secure routines?*
	Environmental pressures on family functioning	*Can family provide adequate nutrition, safe housing, adequate child care/school; are parents under environmental strain?*
Factors inside the family	1. Family composition	*Social genogram*
	2. Attachment	*Assess attachment*
	3. Parenting style	*Inquire about and observe parenting style.*
	4. Family member risks	*Inquire about or screen for maternal depression or mental illness.*
	a. Mental disorder	
	b. Intimate partner violence/ domestic violence	*Inquire about violence or verbal abuse in the home.*
	c. Substance use/abuse	*Inquire about substance abuse in the home.*
	5. Discipline	*Inquire about how the parent disciplines the child.*
	6. Dissolution, disruption, divorce	*Inquire about time, course, emotional tone, and economic effect of family dissolution.*
	7. Foster children and families	*If child is involved with Child Welfare Services, reconstruct the timeline of events to evaluate risk in relation to the child's developmental level.*
Factors outside the family	Economic hardship and financial stress	*Inquire about current financial stability and whether this affects parenting.*
	1. Risks/assets/resilience	*Inquire about strengths, resources, resilience.*
	2. Unemployment, underemployment, poverty, homelessness	*Evaluate if child's "symptoms" are a response to family strain in difficult social environment.*
	3. Working mother	*Inquire about hours of work, work strain.*
	4. Child care	*Is child care formal or informal? How many hours/week?*
	5. School	*Inquire about the quality of school and the child's experience. Bullying?*
	6. The neighborhood	*Be informed about or ask about neighborhood quality and how parents cope with potential dangers.*
	7. Military deployment	*If parents are in military or National Guard, inquire about positive or negative aspects.*
	8. Media: the virtual environment—DVDs, TV, video games, Internet	*Inquire about hours/day of media exposure.*

TOOLS FOR PRACTICE

Medical Decision Support

- *The CRAFFT Screening Tool* (questionnaire), Center for Adolescent Substance Abuse Research (www.ceasar-boston.org/CRAFFT/index.php)
- *Edinburgh Postnatal Depression Scale (EPDS)* (screen), (www2.aap.org/sections/scan/practicingsafety/toolkit_resources/module2/epds.pdf)
- *Mental Health Screening and Assessment Tools for Primary Care* (chart), American Academy of Pediatrics (www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/Mental-Health/Documents/MH_ScreeningChart.pdf)
- *Pediatric Intake Form* (form), Bright Futures (www.brightfutures.org/mentalhealth/pdf/professionals/ped_intake_form.pdf)
- *A Safe Environment for Every Kid* (questionnaire), SEEK Project (www.uspreventiveservicestaskforce.org/Home/GetFileByID/859)

SUGGESTED READINGS

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Chapter 15

PEDIATRIC HISTORY: ASSESSING FUNCTIONING AND MENTAL HEALTH

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NEED FOR PSYCHOSOCIAL SCREENING

Prevalence of Psychosocial Dysfunction

Between 5% and 20% of American children experience psychosocial difficulties that include significant functional impairments and psychiatric disorders defined by the fourth edition of the *Diagnostic Statistical Manual of Mental Disorders (DSM-IV)* and the text revision edition (*DSM-IV-TR*). In addition, a significant number of children and adolescents consider suicide. Childhood psychiatric disorders are estimated to increase by 50% by the year 2020. It's also important to note that with the advent of the fifth edition of the *DSM* (*DSM-5*), these numbers might change slightly. Still, the overall burden of psychiatric symptomatology among children and adolescents is predicted to increase regardless of the nosology used.

Psychiatric diagnoses do not always take into account important developmental and functional assessments. For example, family discord may lead to school phobia or oppositionality in young children and to depression and substance abuse in adolescents. A more holistic nosologic discussion is available through the *Diagnostic and Statistical Manual of Mental Disorders, Primary Care Version (DSM-IV-PC),* a manual defining psychosocial issues within a developmental context.

The *DSM-IV-PC* discusses a broad range of problems, some of which are consistent with formal psychiatric diagnoses and many issues that are clinically relevant despite not meeting full *DSM-IV* criteria. Dysfunction is grouped into 3 main categories: normal variation, problems, and disorders. Normal variation allows for different temperaments, personalities, and developmental paths among healthy children. Problems refer to a broad range of issues that may not meet formal criteria for a discrete psychiatric disorder. For example, the *DSM-IV-PC* recognizes that although a child's anxious reaction to divorce may be a normal and expected developmental response, the child might still be in need of support and services during this difficult time. Finally, disorders refer to specific conditions that meet the *DSM-IV* criteria for a psychiatric disorder. Additionally, the American Academy of Pediatrics (AAP) Task Force on Mental Health has quite appropriately noted that the longitudinal relationship characteristic of primary care allows physicians to recognize psychologic and psychiatric challenges early in the course of the presentation. To this end, primary care pediatricians are ideally suited to engage in secondary and even primary prevention. The long-term relationship with patients ensures a trusting alliance that is necessary for the different kinds of engagement that can be called for in mental health care.

Secondary Consequences of Psychosocial Issues

Beyond mental health concerns, psychosocial issues in primary care have multiple secondary consequences. Psychosocial dysfunction is a major risk factor for unintentional injuries, the most common cause of death in children. Fires, falls from windows, drowning, and motor vehicle accidents are more common among children who have higher rates of psychosocial stressors. Detection of these broader stressors is challenging, given that *DSM-IV* diagnoses generally do not take into account developmental expectations and corresponding functional assessments. Thus, the pediatrician is served best by broadly screening for psychosocial dysfunction rather than focusing exclusively on psychiatric diagnoses. Additionally, specific populations of children have differential risk factors. Foster children, for example, are at a higher risk for teenage pregnancy, school failure, and incarceration. Familiarity with the risk factors that are particular to

special populations allows the physician to ask more pointed and targeted questions during general evaluations.

Barriers to Detecting Psychosocial Difficulties

Despite a high prevalence of psychosocial difficulties encountered by children and adolescents, most of these problems are not detected by primary care physicians. Possible reasons for this lack of recognition include time limitations, hesitancy among physicians to attach possibly stigmatizing labels to children, the absence of widely available and easily implemented screening procedures, lack of adequate training regarding psychosocial issues, and limited resources for referral and treatment. In the absence of a medical home, different physicians might not communicate adequately so that problems can be adequately recognized. Further, migrant families change physicians often, adding again to the burden of knowing a given child well enough to recognize the onset of psychiatric difficulties. Additionally, some evidence suggests that primary care physicians may offer discouraging reactions to the presentation of psychosocial difficulties in their practice. The theoretical benefits of managed care, with its preventive focus and consistent quality assurance activities to improve care processes are being overshadowed by pressures of productivity that have decreased the number of minutes physicians spend with each patient and by barriers to referral. In many communities, the medical referral relationship between primary care and pediatric subspecialists does not extend to psychiatrists because of insurance barriers. However, in principle, managed care should encourage referral by emphasizing screening and quality and, perhaps, lower costs over time. Finally, the negative effect of family psychosocial problems and the resultant childhood toxic stress may be mitigated by strengthening critical socioemotional skills and builiding resiliency early in life.

Reasons to Screen for Psychosocial Dysfunction

The clear epidemiologic burden of psychosocial challenges facing children and adolescents in the context of limited specialty care demands that primary care physicians play an active role in the detection and treatment of this multidimensional issue. The nature of pediatric practice has changed with the decreasing burden of infectious diseases and the growing need to address psychosocial issues ranging from psychiatric disorders to the psychosocial effects of chronic illnesses to injury prevention. As primary care providers, pediatricians have a unique opportunity to detect and address emerging mental health problems in a nonstigmatizing and supportive medical home, while coordinating with mental health specialty services, schools, child care providers, and social services. Primary care physicians also have the opportunity to both identify psychosocial problems and promote social-emotional health and resilience in children and families. Because psychosocial challenges are heterogeneous, and because the average primary care visit includes limited time and increasing psychosocial demands, screening routinely with structured instruments holds the most promise for accurate detection of significant difficulties in the primary care setting.

Goals of Psychosocial Screening

Obtaining a comprehensive psychosocial history is time consuming and inefficient. Practices should develop a structured process that ensures that the families' priorities are addressed, but also that tools for assessing the functioning of the child and family are included in routine health supervision visits. Use of screening tools, such as previsit questionnaires, enable the physician to focus on positive responses as a springboard to further discussion and clarification. Some children's psychosocial issues are recognized because of parental complaints of overt behavioral problems or because of school referral. Less obvious problems, such as dysfunction stemming from divorce or depression, are often identified in the primary care setting. The goal of psychosocial screening is to provide screening methods in harmony with pediatric primary care for early, efficient, and effective recognition of developing psychosocial problems.

STRATEGIES TO INCREASE RECOGNITION OF PSYCHOSOCIAL DYSFUNCTION

Interviewing

Careful attention to developmental aspects of the child's life, such as the child's family, friends, school, play, and mood, will help the pediatrician assess the child's overall function. Additionally, special attention must be paid to "out of home care." Many children, sometimes but not always as a result of poverty or marginalized living situations, are at extreme risk for psychosocial challenges in the absence of secure and stable households. Despite the obvious time involved, face-to-face interviewing, in which high-risk issues are discussed with the patient and parents, offers many advantages. The physician can address key issues directly, communicating to the family the importance of psychosocial issues, thus increasing the likelihood that the family will consider these issues appropriate to bring to the physician's attention.

Raising questions face to face builds trust; examples of clinically relevant questions are available through the AAP *Bright Futures: Guidelines for Health Supervision of Infants, Children, and Adolescents* and are easily accessible online at brightfutures.aap.org. Topics mentioned in both sources include instructions such as the following:

- Assessment of financial resources.
- At intake, ask all parents for a family history of psychiatric disorder (eg, depression, substance use). A family history of depression, anxiety, substance use, and attention-deficit/hyperactivity disorder (ADHD) places the child at high risk.
- Assessment of caretaker skills and reliability.
- At annual visits, ask about parental discord and marital stability.
- Assessment of academic issues.
- Assessment of high-risk behaviors (oppositionality, drug use, etc).

- For newborns, assess parental coping, family support, and maternal depression. A depressed mother has a profound emotional and cognitive effect on an infant; because of the very good response to treatment, the pediatrician can do a real service to the family and the baby through early intervention.
- For toddlers, ask about the child's autonomy and the ability to *separate*.
- For early school-aged children, ask about social functioning.
- For adolescents, ask parents about their child's autonomy, and ask the adolescent about mood and substance use.

Additionally, physicians may refer to the algorithms found in the article "Enhancing Pediatric Mental Health Care: Algorithms for Primary Care through the AAP Task Force on Mental Health" (pediatrics.aappublications.org/content/125/Supplement_3/S109). These algorithms provide a framework for promoting social-emotional health and identifying and responding to new mental health concerns, whether raised by parents in scheduling the visit or suggested by the data collection and assessment activities from routine screening.

Screening Tools

Parent Questionnaires

Because of the time constraints inherent in a face-to-face approach, alternative strategies have been developed to screen more efficiently for psychosocial difficulties. Ideally, these tools are used to supplement face-to-face time. The Achenbach Child Behavior Checklist (CBCL) is the most studied and best validated behavioral screening device available for children aged 4 to 16 years. The Achenbach CBCL is completed by the child's parents and is divided into 2 distinct item groups (behavior problems and school competency). Although the results of the Achenbach CBCL are reliable and valid, the main drawbacks to the use of this instrument include length of administration (more than 100 items requiring approximately 20 minutes of the parents' time) and some complexity in methods for scoring and interpreting the results of the questionnaire.

A less cumbersome alternative to the Achenbach CBCL is the Pediatric Symptom Checklist (PSC), a 35-item survey also given to the parents and requiring only a few minutes to complete. In addition, the results of the PSC can be scored quickly, with 2 points assigned to each question answered "often," 1 point assigned to each answered "sometimes," and 0 points assigned to each answered "never." Administration and scoring commonly take 3 to 5 minutes. A score greater than 28 suggests a 70% likelihood that the child has significant psychosocial difficulties; scores less than 28 suggest a greater than 95% likelihood that the child has no substantial psychosocial problems. Thus, if the parents complete the PSC in the waiting room and have it scored by a receptionist or clinical assistant, then the pediatrician can quickly recognize and more closely evaluate significant psychosocial issues.

However, although the PSC works well in adolescent populations, it is somewhat hampered in this age group by the parents' limitations in correctly assessing, through a questionnaire, their child's intrapsychic state. Specifically, some parents will not know that their child is depressed because the child seems to be in reasonable spirits and functioning well; thus, the PSC will, in this circumstance, yield a false-negative result. Despite this difficulty, because the PSC primarily assesses function, it still yields efficient and important information that can direct further inquiry.

A relatively new screening device is the Strengths & Difficulties Questionnaire. This instrument includes 25 items that assess specifically for emotional difficulties; problems with conduct, hyperactivity, and inattention; peer relationship indicators; and prosocial behavior. This screening tool is completed by parents and teachers of children aged 4 to 16 years, and additional versions exist for assessing younger children. The Strengths & Difficulties Questionnaire is similar to the PSC, but is perhaps slightly more complicated to score.

Finally, physicians who suspect specific psychiatric syndromes such as anxiety or depression can utilize specialized screening tools. For depression, the Patient Health Questionnaire-9 (PHQ-9) can be useful, and, for anxiety, the Generalized Anxiety Disorder-7 (GAD-7) can be of benefit. These are both short and easy to administer in the office or waiting area.

Patient Questionnaires

For young children, the Human Figure Drawing Screening Device has been found useful in elucidating occult anxiety and depression.

The issue of identifying the adequately functioning, but depressed, teenager can be addressed in several ways. Columbia University has started a nationwide program called TeenScreen. This program helps schools and physicians construct different means by which adolescents can be screened for depression and suicidality. Interestingly, some political opposition exists to this program, with several political groups suggesting that not all Americans are in favor of screening children for psychiatric difficulties. A more traditional approach involves use of the Beck Depression Inventory, completed by the adolescent at the time of the primary care visit. Twenty percent or more of teenagers have scores that raise concerns using this screening instrument.

Specific Screening

Some pediatric practices have gone beyond general psychosocial and depression screening to help identify children with autism, using the Modified Checklist for Autism in Toddlers (M-CHAT) and the Parents' Evaluation of Developmental Status (PEDS), and screening for adolescent substance use. Offering critiques or endorsements of every screening device available is not the goal of this chapter. All of the methods discussed have utility, and physicians must choose an instrument that best addresses their practice, level of interest, and patient population.

Assessing Severity of Psychosocial Dysfunction

When psychosocial issues are identified through screening or a clinical interview, patients should be assessed for the severity of the impairment in functioning. Although conditions such as psychosis or

serious suicidal ideation are clearly severe, other problems, such as depression or anxiety, are quite variable in their severity. Not all cases of depression, for example, need specialized treatment, although some depressed children require an aggressive and multimodal approach and even hospitalization.

An assessment of severity includes the following:

1. *Symptoms:* number, frequency, and duration of symptoms, and places where the symptoms are experienced
2. *Functioning:* developmental effect on functioning in key areas such as family, friends, school, activities, and self-esteem
3. *Burden of suffering:* intensity of suffering, duration, limitations on family activities, danger to self and others, and intrusion into developmental tasks or daily activities

FACTORS AFFECTING PSYCHOSOCIAL HEALTH

In the process of screening and assessment for psychosocial health, understanding risk factors that may be associated with future problems is also important. Several biologic and environmental factors may be protective against the risk of adversity leading to serious psychosocial problems. Table 15-1 outlines both protective and risk factors for psychosocial difficulties. The number of moderate risk factors can have a cumulative effect on a child's dysfunction that is greater than the effect of any single severe risk factor. Children facing 3 or more risk factors have a very high likelihood of psychosocial problems. Individual risk factors that have special significance include single-parent households and poverty.

The issue of poverty deserves special mention. Although numerous studies have connected low socioeconomic status with increased risk of psychosocial dysfunction, research suggests that pediatricians tend to address a larger proportion of psychosocial concerns in highly educated families than in less-educated families. A potential explanation for this discrepancy is that more highly educated parents might feel more comfortable bringing psychosocial issues to their pediatrician's attention, whereas less-educated parents might not realize that the pediatrician's office is appropriate for psychosocial inquiries. In addition, some studies have shown that middle- to upper-class parents tend to over-report their children's psychosocial problems, whereas lower-class parents tend to under-report. A recently posited alternative explanation for why poverty is a risk factor includes the possibility that some mothers are more likely to ask the community for support with their child's psychosocial difficulties. This practice may be more prevalent in lower-income families. All of these findings demonstrate the need for a thorough and systematic review of psychosocial issues in all patients within a pediatric practice.

BRIEF EVALUATION

Many psychosocial problems will be elucidated through focused interviewing or using different screening instruments. For best results, physicians should be relatively consistent with their screening instruments, familiarizing themselves with one instrument with which they and their colleagues are most comfortable. In addition, patients might have a definite psychosocial complaint, often mentioned by parents or school personnel. At this point, the physician should attempt to elaborate the symptoms, further defining the nature of the complaint. Risk factors and developmental concerns should be considered, and the child's daily functioning should be examined. The SEEK (Safe Environment for Every Kid) model of pediatric care is an example of a program that was developed to help primary care physicians identify and address psychosocial problems that impair parental and family functioning and jeopardize children's

Table 15-1 Children's Well-Being: Protective and Risk Factors

HEALTH	GOOD HEALTH	CHRONIC DISEASE, ILL HEALTH
Temperament	Example: pleasant mood	Example: negative mood, irritable
Cognitive status	Normal intelligence quotient (IQ) (particularly verbal)	Learning disability or low IQ
Emotional health	Good mental health function	Pre-existing emotional disorder
Sociability	Good peer relations	Poor peer relations
Child reaction to stress	Perceives stress as limited; does not blame self	Perceives continued threat; blames self
Quality of attachment	High quality, high continuity; securely attached	Low quality, discontinuous; ambivalent, insecurely attached
Parent competence	Competent	Incompetent
Family resources	Adequate economic resources	Poverty or discrimination
Quality, stability, safety of environment	Adequate, stable, safe	Inadequate, unstable, unsafe
Family relationships	Good communication; little conflict	Poor communication; excessive conflict
Emotional and physical health of caregivers	Caregivers in good emotional and physical health	Mental illness or physical illness in caregivers
Availability of or access to community resources	High access	Low access

physical and mental health. (Dubowitz) Several guidelines will be helpful in this process.

1. For younger children, observe them while directing questions to the parents.
2. For school-aged children, use confirmatory questions, if possible, without parents being present.
3. For adolescents, perform a separate interview with the patient alone. Assess important issues such as substance use and depression. Inquire about sexual activity. Consider parental functioning, especially abuse, depression, and substance use.
4. Review relevant risk factors and potentially protective factors.
5. Assess safety, paying special attention to potential accidents, suicidal ideation, and risk-taking behaviors.
6. Complete a severity estimate using the Achenbach CBCL and the PSC formats, ranking the current issue as mild, moderate, or severe.

Once information is gathered, the presenting complaint should be categorized as either a normal variation that requires no further action or a problem that requires special consideration. Many issues can be addressed at the primary care level, often with comanagement by mental health professionals or school personnel. Other, more serious problems require outside referral for evaluation by a specialist and, possibly, ongoing treatment. The most severe cases often require emergency referral.

THE FUTURE IS NOT QUITE HERE

The future of psychosocial screening is ripe with promise. Perhaps the most exciting aspect concerns the possible use of genetic screening to subtype risk factors for psychosocial difficulties and to predict treatment response. For example, Caspi and colleagues reported an autosomal recessive genotype of the serotonin transporter gene that is strongly correlated with the propensity to develop depression after a negative life event. Patients who were heterozygous or autosomal dominant seemed significantly less at risk for psychosocial difficulties after difficult events. Importantly, however, the technology and the understanding of these and similar findings are not yet applicable to routine practice; rather, they represent important directions of future inquiries. Similarly, numerous organizations suggest that sophisticated neuroimaging assays and the use of electroencephalographic evaluations have the capacity to predict the onset of psychosocial problems. The current standard of care and the state of the research concerning these techniques suggest that the information gleaned from these evaluations is no better than a careful clinical evaluation. For this reason, at this point, little practical stock can be placed in these tests, but they do hold great promise for the future.

CHANGING PRACTICE ENVIRONMENT AND NEXT STEPS

Although the epidemiology of pediatric practice has shifted dramatically from infectious disease to immunologic and psychosocial concerns, the changes in reimbursement secondary to managed care constraints have made psychosocial screening and referral for appropriate treatment increasingly difficult. For most children in the United States, mental health services are carved out of pediatric care, with financial incentives that discourage referral and comprehensive treatment. These carved-out companies limit the role of psychiatrists primarily to medication management, creating an environment increasingly overemphasizing psychotropic medication at the expense of both comprehensive and alternative treatments. Furthermore, capitation may be an additional disincentive to referral to specialty services.

However, innovative practices may be able to provide more children with adequate treatment in spite of the current health care insurance climate.

General psychosocial screening usually results in a substantial increase in recognition and an increase in referral rate from the 1% to 2% range to 4%. Many practices have made use of new technologies to set up electronic questionnaires on tablets in the waiting room or from home through the Internet. Built-in screening tests can be determined by the child's age and risk factors. For example, a family history of ADHD or a cluster of positive answers to school dysfunction questions may elicit, through internal logic, an ADHD screening questionnaire. Given the prevalence of disorders, some pediatricians already have mental health professionals in their practices to provide follow-up to screening, consultation, and ongoing services. The idea of the office social worker being at the hub of referral services, providing individual, family, and group treatment in the pediatric office setting, can be easily imagined. These groups might include preventive efforts regarding recent divorce, ongoing support for parents raising children with ADHD, or treatment for adolescents using substances or dealing with depression. Depending on the local reimbursement climate, screening, evaluation, and in-office services may be covered and self-sustaining.

Addressing a child's psychosocial development and dysfunction is among the highest priorities for parents who experience their child's emotional suffering on a daily basis. Parents are important partners in supporting the health and well-being of children, but they sometimes need help building their own capacity to effectively support their children. The Strengthening Families Protective Factors Framework (www.cssp.org/reform/strengtheningfamilies) identifies the protective factors that all families need as parental resilience, knowledge of parenting and child development, social connections, concrete supports in the time of need, and social-emotional competence of children. To this end, the primary care pediatric office, with adequate reimbursement, is in an ideal setting to provide crucial screening and to initiate important treatments.

TOOLS FOR PRACTICE

Community Advocacy and Coordination

- *Trauma Guide* (Web page), American Academy of Pediatrics (www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/healthy-foster-care-america/Pages/Trauma-Guide.aspx)

Medical Decision Support

- *Ages & Stages Questionnaires* (screen) (agesandstages.com)
- *The ASEBA Approach* (checklist), Achenbach System of Empirically Based Assessment (www.aseba.org)
- *The CRAFFT Screening Tool* (screen), Center for Adolescent Substance Abuse Research (www.ceasar-boston.org/CRAFFT/index.php)
- *Edinburgh Postnatal Depression Scale (EPDS)* (questionnaire), Cox JL, Holden JM, Sagovsky R (www2.aap.org/sections/scan/practicingsafety/toolkit_resources/module2/epds.pdf)
- *Generalized Anxiety Disorder 7 Item (GAD-7) Scale* (questionnaire), Substance Abuse and Mental Health Services Administration (www.integration.samhsa.gov/clinical-practice/GAD708.19.08Cartwright.pdf)
- *Mental Health Screening and Assessment Tools for Primary Care* (chart), American Academy of Pediatrics (www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/Mental-Health/Documents/MH_ScreeningChart.pdf)
- *Modified Checklist for Autism in Toddlers* (screen), M-CHAT (www.m-chat.org)
- *Pediatric Intake Form* (template), Bright Futures (www.brightfutures.org/mentalhealth/pdf/professionals/ped_intake_form.pdf)
- *Pediatric Symptom Checklist* (screen), Massachusetts General Hospital (www.massgeneral.org/psychiatry/services/psc_home.aspx)
- *PEDS* (screen), PEDStest.com (www.pedstest.com)
- *Screen for Child Anxiety Related Disorders (SCARED): Child Version* (questionnaire), University of Pittsburgh (www.psychiatry.pitt.edu/sites/default/files/Documents/assessments/SCARED%20Child.pdf)
- *Screen for Child Anxiety Related Disorders (SCARED): Parent Version* (questionnaire), University of Pittsburgh (www.psychiatry.pitt.edu/sites/default/files/Documents/assessments/SCARED%20Parent.pdf)
- *SEEK Parent Questionnaire* (screen), University of Maryland School of Social Work (theinstitute.umaryland.edu/seek/seek_pq.cfm)
- *Strengths and Difficulties Questionnaires* (screen), Youth in Mind (www.sdqinfo.com)

SUGGESTED READINGS

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Chapter 16

PEDIATRIC PHYSICAL EXAMINATION: INTERPRETATION OF FINDINGS

Douglas N. Homnick, MD, MPH

It is assumed that the pediatrician has learned from training and practice to perform the physical examination specific to the age of the child encountered and consistent with the tried and true formula of general and close visual inspection, olfaction, manipulation, palpation, percussion, and auscultation. This chapter is dedicated to the physical examination and its findings, defined as what the physician discovers during the examination and his or her knowledge of conditions commonly encountered in pediatric practice. It is also convenient to relate these findings to specific age groups in order to enhance the efficiency of the development of differential diagnoses. Tables of common diagnoses associated with specific examination findings are provided. As is often the case, a single finding may produce a differential diagnosis spanning multiple organ systems, and the specifics of that finding as it relates to a particular organ or system can be found in the appropriate chapters of this book. Also, the order in which these findings are presented is based generally on a "head to toe" examination, which is by no means adaptable to every situation. While many textbooks are available on the subjects of pediatric and adult physical diagnosis, this chapter is meant to be a quick and convenient resource for those encountering a specific finding or multiple findings during a comprehensive physical examination.

VITAL SIGNS AND ANTHROPOMETRICS

Temperature

The definition of fever is a core temperature of 100.4°F (38°C) or higher. Any condition that affects hypothalamic regulation can affect temperature. The most common cause of fevers overall in pediatrics is infection from the release of exogenous or endogenous pyrogens. Causes of fever by age group are listed in Table 16-1.

Special conditions causing elevation in temperature include hyperthermia from exposure to ambient heat with insufficient heat elimination mechanisms (eg,

Table 16-1 Common Findings in the Office Examination

VITAL SIGN	FINDING	NEWBORN AND INFANT	CHILD	ADOLESCENT
Fever, hyperthermia	Temperature ≥ 100.4°F (38°C)	Infection, overwrapping, excessive environmental heat	Infection, malignant hyperthermia, increased environmental heat (heat exhaustion, heat stroke), rheumatic disease, hyperthyroidism, inflammatory bowel disease, malignancy	Same as child
Hypothermia	Temperature ≤95.9°F (35.5°C)	Infection, underwrapping, insufficient environmental heat	Cold exposure, hypothyroidism, hypoglycemia, CNS neoplasms and other dysfunction (including stroke), chronic malnutrition	Same as child
Heart rate and rhythm	Varies with respiration (sinus arrhythmia)	Normal	Normal	Normal but less common
	Rapid heart rate (tachycardia)	Fever, fear, pain, infection, activity, anemia, drug toxicity (eg, adrenergics, anticholinergics), cardiac disease	Same as infant, but also psychostimulants, antihistamines, early shock, hyperthyroidism	Same as child and infant, but also other illicit substances, eg, cocaine
	Slow heart rate (bradycardia)	Cardiac conduction defects, drug toxicity, malnutrition	Same as infant, but also consider toxic ingestion, hypothyroidism	Same as infant and child, but also consider illicit drug use or toxic ingestion
	Heart rate lability	Drug toxicity, severe malnutrition	Same as infant, but also consider toxic ingestion	Same as infant and child, but also consider illicit drug use
Respiratory rate	Cessation of breathing (apnea)	Prematurity, gastroesophageal reflux disease, tracheoesophageal fistula, choanal atresia, Pierre Robin syndrome, sepsis, metabolic (electrolyte, acid-base disorders), drug toxicity, suffocation, positional asphyxia, sudden infant death syndrome, central hypoventilation syndrome	Tonsillar hypertrophy (significant), severe pneumonia or asthma, epiglottitis, bacterial tracheitis, retropharyngeal abscess, CNS lesion/infection/trauma, toxic ingestion	Obesity, CNS lesion/infection/trauma, severe pneumonia or asthma, toxic ingestion
	Rapid respirations (tachypnea)	Transient tachypnea of the newborn, infection, cardiac disease, fever	Fear/anxiety, infection, asthma, acidosis, CNS lesion, toxic ingestion	Same as child, but anxiety more common
	Slow respirations (bradypnea)	CNS lesions, hydrocephalus, drug toxicity, respiratory muscle fatigue	CNS lesions, drug toxicity, respiratory muscle fatigue	Same as child
	Deep and or labored respirations (dyspnea)	CNS lesions, infection, drug toxicity, cardiac dysfunction, pulmonary dysfunction, metabolic disease	CNS lesions, drug toxicity, fear/anxiety, pulmonary dysfunction, cardiac dysfunciton	Same as child, but anxiety more common
Blood pressure	High (hypertension)	Renal artery stenosis, renal vein thrombosis, renal parenchymal disease, increased intracranial pressure, intracranial hematoma (trauma), congenital adrenal hyperplasia, tumor, drugs, hypercalcemia, fluid overload, hyperthyroidism, coarctation of the aorta, steroid toxicity	Hereditary, renal parenchymal disease, hyperthyroidism, Cushing disease, hyperaldosteronism, increased intracranial pressure, tumor, pain/anxiety, drugs	Same as child, but substance abuse is more common, stress/anxiety

Continued

Table 16-1 Common Findings in the Office Examination—cont'd

VITAL SIGN	FINDING	NEWBORN AND INFANT	CHILD	ADOLESCENT
	Low (hypotension)	Hypovolemia, adrenal insufficiency, dehydration, sepsis, drugs, heart disease	Same as newborn, but also consider heart disease, steroid withdrawal (Addisonian crisis), CNS lesion, diabetes, heat stress	Same as child, but consider toxic ingestion, eating disorder
	Changes with position (orthostatic changes)	Rare	Prolonged bed rest, hypovolemia, autonomic dysfunction, malnutrition.	Same as child, but consider anorexia nervosa and bulimia

CNS, central nervous system.

sweating), malignant hyperthermia, heat cramps, heat exhaustion, and heat stroke. Malignant hyperthermia, an inherited disorder, may follow administration of inhalation anesthetics or succinylcholine. Heat cramps are painful, forceful contractions of large muscle groups usually later in exercise. Heat exhaustion includes fatigue, malaise, headache, dizziness, hypotension, tachycardia, nausea, and vomiting from intravascular volume depletion. Heat stroke includes elevation of temperature with mental status changes. These findings are also listed in Table 16-1.

Hypothermia results from hypothalamic dysregulation, exposure to cold with reduced ability to retain heat (increased surface area in a young infant), insufficient thermal protection (coverings), and inability to shiver. The definition of hypothermia is a core temperature of less than 96.0°F (35.5°C). Conditions associated with hypothermia are listed in Table 16-1.

Heart Rate and Rhythm

Examination through auscultation and palpation gives a great deal of information about heart rate and rhythm. Commonly encountered findings include sinus arrhythmia, increased rate during inspiration and decreased rate during expiration (normal), tachycardia, rate above the normal rate for age, bradycardia, heart rate below normal range for age, heart rate lability, changes in rate and rhythm at rest, and irregular rhythms that may be caused by conduction abnormalities. Normal heart rate for age is found in Table 16-2, and diagnostic possibilities from these findings are found in Table 16-1.

Respiratory Rate

Knowledge of normal respiratory rates by age group is useful to further define the presence or absence of cardiopulmonary and metabolic disease (Figure 16-1). Findings encountered during the pediatric physical examination include apnea (cessation of breathing for more than 20 seconds); tachypnea (respiratory rate above normal); bradypnea (respiratory rate below normal); dyspnea (shortness of breath); deep respirations with use of accessory muscles of respiration; Kussmaul respirations (rapid, heavy, deep breathing); and Cheyne-Stokes respiration (alternating periods of rapid and slow breathing). Retractions from greater chest wall compliance and grunting are signs of significant lower respiratory disease in infants. Use of accessory muscles of respiration (sternocleidomastoids, scalenes) is associated with increased respiratory effort in older children and adolescents. Conditions associated with these findings are also found in Table 16-1 and Table 16-3.

Table 16-2 Average Heart Rate for Infants and Children at Rest

AGE	HEART RATE AT REST (BEATS/MIN)
Birth–1 mo	100–180
1–12 mo	100–180
1–3 y	70–110
4–6 y	70–110
7–12 y	70–110
13–19 y	55–90

Adapted from Monaghan A. Detecting and managing deterioration in children. *Paediatric Nursing.* 2005;17:32–35.

Blood Pressure

Knowledge of normal pediatric blood pressures at different ages assists in the interpretation of blood pressure measurements. These are found in Table 16-4 and Table 16-5. Most blood pressure measurements are necessarily peripheral measurements, most commonly obtained with a sphygmomanometer. Automated blood pressure relies on oscillometry and is less examiner dependent than manual cuff measurements. Findings, based on a knowledge of normal values, include hypertension, high blood pressure, hypotension, low blood pressure, shock, initial tachycardia and later perfusion abnormalities in children, and orthostatic changes, change of blood pressure (and pulse) with position. Orthostatic hypotension is the most commonly encountered finding. Findings related to abnormalities in blood pressure are shown in Table 16-1.

Anthropometrics

Anthropometrics consists of height, weight, head circumference, and the calculated value of body

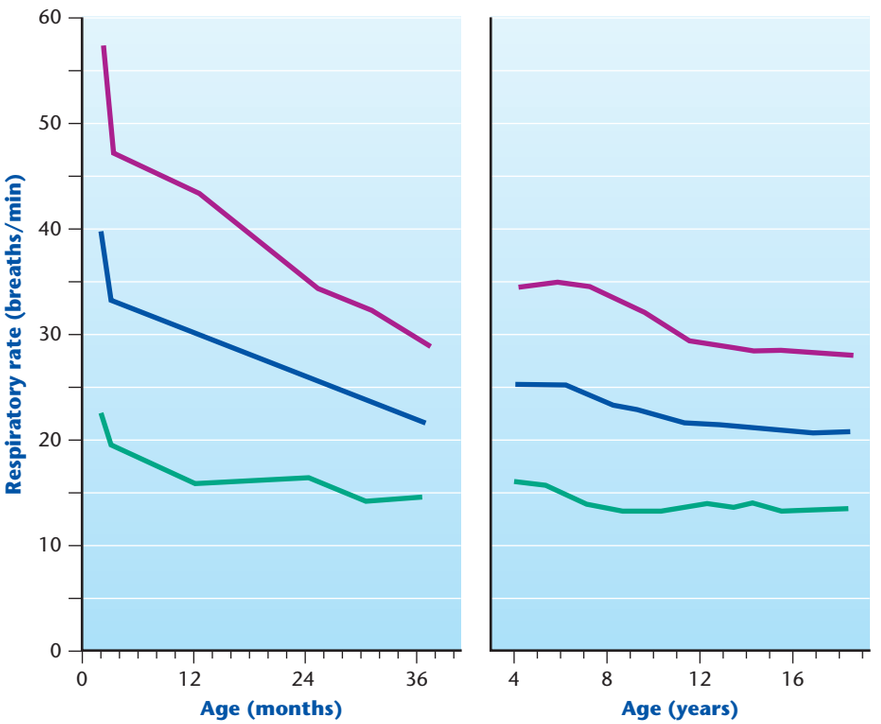

Figure 16-1 Normal respiratory rate for children. *(Adapted from Pasterkamp H. The history and physical examination. In: Chernick V, Boat TF, Wilmott RW, Bush A, eds.* Kendig's Disorders of the Respiratory Tract in Children. *7th ed. Philadelphia, PA: Elsevier Saunders; 2006: 77, with permission from Elsevier.)*

Table 16-3 Common Findings in the Chest Wall and Lungs

SITE	FINDING	NEWBORN AND INFANT	CHILD	ADOLESCENT
Chest wall	Asymmetry of anatomy	Poland syndrome, rib or thoracic vertebral anomaly	Pectus deformity, rib or vertebral anomaly, scoliosis, Poland syndrome	Pectus deformity, scoliosis, Poland syndrome
	Asymmetry of chest motion	Unilateral diaphragmatic paresis/paralysis, pneumothorax	Neuromuscular disease, diaphragmatic paresis, paralysis, pneumothorax, foreign body	Neuromuscular disease, pneumothorax, foreign body
	Large thorax	Masses including abdominal contents, bronchiolitis	Asthma, cystic fibrosis	Asthma, cystic fibrosis
	Small thorax	Neuromuscular disease, bony dysplasias	Costochondritis, xyphoiditis, Tietze's syndrome, bony dysplasias, trauma, infection	Costochondritis, xyphoiditis, slipping rib syndrome, Tietze's syndrome, bony dysplasias, trauma, infection, gynecomastia
	Dullness to percussion	Fluid in thorax, mass in thorax (bowel, tumor), hypoplastic lung	Fluid in thorax, tumor, consolidation	Same as child
	Retractions	Increased work of breathing from any cause	Same as infant	Same as child
	Accessory muscle use	Increased work of breathing from any cause	Same as infant	Same as child, includes panic/hyperventilation

Continued

Table 16-3 Common Findings in the Chest Wall and Lungs—cont'd

SITE	FINDING	NEWBORN AND INFANT	CHILD	ADOLESCENT
Lung	Stridor	Vocal cord paresis/paralysis, vocal cord or laryngeal lesion/anomaly, GERD, vascular ring, mediastinal mass, chronic aspiration syndromes, tetany, airway trauma, subglottic stenosis	Vocal cord paresis/paralysis, infection (including laryngotracheobronchitis and epiglottitis), vocal cord or laryngeal lesion/anomaly, GERD, vascular ring, chronic aspiration syndromes, mediastinal mass, foreign body, airway trauma	Vocal cord paresis/paralysis, vocal cord dysfunction, infection including epiglottis, GERD, mediastinal mass, toxins, foreign body, airway trauma, laryngeal lesions (including neoplasm)
	Decreased vocal fremitus/dullness to percussion, decreased breath sounds	Consolidation, intrathoracic fluid or air, atelectasis, bowel or liver in chest, masses	Consolidation, intrathoracic fluid or air, masses, atelectasis, pulmonary malformations	Same as child
	Coarse, wet crackles and snaps (rhonchi)	Aspiration syndromes, ineffective cough, pneumonia, GERD	Aspiration syndromes, pneumonia, tracheitis, bronchitis, asthma, cystic fibrosis, GERD	Aspiration syndromes, pneumonia, tracheitis, bronchitis, asthma, cystic fibrosis, GERD, primary smoking
	Fine crackles (also termed rales and crepitations)	Consolidation, heart failure, aspiration syndromes, bronchiolitis, pneumonia (viral, bacterial)	Consolidation, heart failure, asthma, pneumonia (viral, bacterial), aspiration syndromes	Consolidation, heart failure, asthma, pneumonia (viral, bacterial), aspiration syndromes
	Monophonic wheeze (fixed)	Tracheomalacia, airway compression because of vascular/GI/lung anomalies, mediastinal masses	Focal tracheomalacia, foreign body, airway compression because of vascular/GI/lung anomalies, mediastinal masses	Foreign body, masses, lung and vascular anomalies
	Polyphonic wheeze (dynamic)	Aspiration syndromes, bronchiolitis, heart failure, asthma	Aspiration syndromes, heart failure, asthma	Same as child
	Pleural rub	Pleuritis secondary to infection, neoplasm, rheumatic vasculitic disease, and trauma; with early pleural effusion of any etiology	Same as infant	Same as child
Cyanosis	Blue tinge to mucus membranes	Cardiac disease, infection/sepsis, aspiration syndromes, apnea, hypoventilation, atelectasis, methemoglobinemia	Cardiac disease, infection, atelectasis, intrathoracic fluid or air, toxin, methemoglobinemia	Same as child
Clubbing	Increased subungual tissue	Rare	Chronic cardiac, respiratory, or hepatic disease; familial	Same as child

GERD, gastroesophageal reflux disease; *GI,* gastrointestinal

mass index (BMI = wt/ht^2), all of which may be displayed as absolute numbers or percentiles for age and gender. Knowledge of normal anthropometrics, including head circumference, is essential to the pediatrician, and these are found in Figure 16-2, Figure 16-3, Figure 16-4, and Figure 16-5. Charts of head circumference and growth are useful for serial measurement and monitoring during regular office visits, and deviation from these curves may be the first sign of chronic disease or caregiver neglect. Abnormal findings related to height, weight, and head circumference are addressed in this chapter's discussion of Head, Eyes, Ears, Nose, and Throat and Endocrinology.

Table 16-4 Blood Pressure Levels for Boys by Age and Height Percentile[a]

AGE (YEAR)	BP (PERCENTILE)	SYSTOLIC BP (mm HG) PERCENTILE OF HEIGHT							DIASTOLIC BP (mm HG) PERCENTILE OF HEIGHT						
		5th	10th	25th	50th	75th	90th	95th	5th	10th	25th	50th	75th	90th	95th
1	50th	80	81	83	85	87	88	89	34	35	36	37	38	39	39
	90th	94	85	97	99	100	102	103	49	50	51	52	53	53	54
	95th	98	99	101	103	104	106	106	54	54	55	56	57	58	58
	99th	105	106	108	110	112	113	114	61	62	63	64	65	66	66
2	50th	84	85	87	88	90	92	92	39	40	41	42	43	44	44
	90th	97	99	100	102	104	105	106	54	55	56	57	58	58	59
	95th	101	102	104	106	108	109	110	59	59	60	61	62	63	63
	99th	109	110	111	113	115	117	117	66	67	68	69	70	71	71
3	50th	86	87	89	91	93	94	95	44	44	75	46	47	48	48
	90th	100	101	103	105	107	108	109	59	59	60	61	62	63	63
	95th	104	105	107	109	110	112	113	63	63	64	65	66	67	67
	99th	111	112	114	116	118	119	120	71	71	72	73	74	75	75
4	50th	88	89	91	93	95	96	97	47	48	49	50	51	51	52
	90th	102	103	105	107	109	110	111	62	63	64	65	66	66	67
	95th	106	107	109	111	112	114	115	66	67	68	69	70	71	71
	99th	113	114	116	118	120	121	122	74	75	76	77	78	78	79
5	50th	90	91	93	95	96	98	98	50	51	52	53	54	55	55
	90th	104	105	106	108	110	111	112	65	66	67	68	69	69	70
	95th	108	109	110	112	114	115	116	69	70	71	72	73	74	74
	99th	115	116	118	120	121	123	123	77	78	79	80	81	81	82
6	50th	91	92	94	96	98	99	100	53	53	54	55	56	57	57
	90th	105	106	108	110	111	113	113	68	68	69	70	71	72	72
	95th	109	110	110	114	115	117	117	72	72	73	74	75	76	76
	99th	116	117	117	121	123	124	125	80	80	81	82	83	84	84
7	50th	92	94	95	97	99	100	101	55	55	56	57	58	59	59
	90th	106	107	109	111	113	114	115	70	70	71	72	76	74	74
	95th	110	111	113	115	117	118	119	74	74	75	76	77	78	78
	99th	117	118	120	122	124	125	126	82	82	83	84	85	86	86
8	50th	94	95	97	99	100	102	102	56	57	58	59	60	60	61
	90th	107	109	110	112	114	115	116	71	72	72	73	74	75	76
	95th	111	112	114	116	118	119	120	75	76	77	78	79	79	80
	99th	119	120	122	123	125	127	127	83	84	85	86	87	87	88
9	50th	95	96	98	100	102	103	104	57	58	59	60	61	61	62
	90th	109	110	112	114	115	117	118	72	73	74	75	76	76	77
	95th	113	114	116	118	119	121	121	76	77	78	79	80	81	81
	99th	120	121	123	125	127	128	129	84	85	86	87	88	88	89
10	50th	97	98	100	102	103	105	106	58	59	60	61	61	62	63
	90th	111	112	114	115	117	119	119	73	73	74	75	76	77	78
	95th	115	116	117	119	121	122	123	77	78	79	80	81	81	82
	99th	122	123	125	127	128	130	130	85	86	86	88	88	89	90
11	50th	99	100	102	104	105	107	107	59	59	60	61	62	63	63
	90th	113	114	115	117	119	120	121	74	74	75	76	77	78	78
	95th	117	118	119	121	123	124	125	78	78	79	80	81	82	82
	99th	124	125	127	129	130	132	132	86	86	87	88	89	90	90
12	50th	101	102	104	106	108	109	110	59	60	61	62	63	63	64
	90th	115	116	118	120	121	123	123	74	75	75	76	77	78	79
	95th	119	120	122	123	125	127	127	78	79	80	81	82	82	83
	99th	126	127	129	131	133	134	135	86	87	88	89	90	90	91
13	50th	104	105	106	108	110	111	112	60	60	61	62	63	64	64
	90th	117	118	120	122	124	125	126	75	75	76	77	78	78	79
	95th	121	122	124	126	128	129	130	79	79	80	81	82	83	83
	99th	128	130	131	133	135	136	137	87	87	88	89	90	91	91

Continued

Table 16-4 Blood Pressure Levels for Boys by Age and Height Percentile—cont'd

AGE (YEAR)	BP (PERCENTILE)	SYSTOLIC BP (mm HG) PERCENTILE OF HEIGHT							DIASTOLIC BP (mm HG) PERCENTILE OF HEIGHT						
		5th	10th	25th	50th	75th	90th	95th	5th	10th	25th	50th	75th	90th	95th
14	50th	106	107	109	111	113	114	115	60	61	62	63	64	65	65
	90th	120	121	123	125	126	128	128	75	76	77	78	79	79	80
	95th	124	125	127	128	130	132	132	80	80	81	82	83	84	84
	99th	131	132	134	136	138	139	140	87	88	89	90	91	92	92
15	50th	109	110	112	113	115	117	117	61	62	63	64	65	66	66
	90th	122	124	125	127	129	130	131	76	77	78	79	80	80	81
	95th	126	127	129	131	133	134	135	81	81	82	83	84	85	85
	99th	134	135	136	138	140	142	142	88	89	90	91	92	93	93
16	50th	111	112	114	116	118	119	120	63	63	64	65	66	67	67
	90th	125	126	128	130	131	133	134	78	78	79	80	81	82	82
	95th	129	130	132	134	135	137	137	82	83	83	84	85	86	87
	99th	136	137	139	141	143	144	145	90	90	91	92	93	94	94
17	50th	114	115	116	118	120	121	122	65	66	66	67	68	69	70
	90th	127	128	130	132	134	135	136	80	80	81	82	83	84	84
	95th	131	132	134	136	138	139	140	84	85	86	87	87	88	89
	99th	139	140	141	143	145	146	147	92	93	93	94	95	96	97

BP, blood pressure; *SD,* standard deviations.
[a]The 90th percentile is 1.28 SD, 95th percentile is 1.645 SD, and the 99th percentile is 2.326 SD over the mean.
From US Dept of Health and Human Services, National Institutes of Health, and National Heart, Lung and Blood Institute. *The Fourth Report on the Diagnosis, Evaluation, and Treatment of High Blood Pressure in Children and Adolescents.* National Institutes of Health publication 05-5267. Bethesda, MD: US Dept of Health and Human Services, National Institute of Health; 2005.

Table 16-5 Blood Pressure Levels for Girls by Age and Height Percentile[a]

AGE (YEAR)	BP (PERCENTILE)	SYSTOLIC BP (mm HG) PERCENTILE OF HEIGHT							DIASTOLIC BP (mm HG) PERCENTILE OF HEIGHT						
		5th	10th	25th	50th	75th	90th	95th	5th	10th	25th	50th	75th	90th	95th
1	50th	83	84	85	86	88	89	90	38	39	39	40	41	41	42
	90th	97	97	98	100	101	102	103	52	53	53	54	55	55	56
	95th	100	101	102	104	105	106	107	56	57	57	58	59	59	60
	99th	108	108	109	111	112	113	114	64	64	65	65	66	67	67
2	50th	85	85	87	88	89	91	91	43	44	44	45	46	46	47
	90th	98	99	100	101	103	104	105	57	58	58	59	60	61	61
	95th	102	103	104	105	107	108	109	61	62	62	63	64	65	65
	99th	109	110	111	112	114	115	116	69	69	70	70	71	72	72
3	50th	86	87	88	89	91	92	93	47	48	48	49	50	50	51
	90th	100	100	102	103	104	106	106	61	62	62	63	64	64	65
	95th	104	104	105	107	108	109	110	65	66	66	67	68	68	69
	99th	111	111	113	114	115	116	117	73	73	74	74	75	76	76
4	50th	88	88	90	91	92	94	94	50	50	51	52	52	53	54
	90th	101	102	103	104	106	107	108	64	64	65	66	67	67	68
	95th	105	106	107	108	110	111	112	68	68	69	70	71	71	72
	99th	112	113	114	115	117	118	119	76	76	76	77	78	79	79
5	50th	89	90	91	93	94	95	96	52	53	53	54	55	55	56
	90th	103	103	105	106	107	109	109	66	67	67	68	69	69	70
	95th	107	107	108	110	111	112	113	70	71	71	72	73	73	74
	99th	114	114	116	117	118	120	120	78	78	79	79	80	81	81

Table 16-5 Blood Pressure Levels for Girls by Age and Height Percentile—cont'd

AGE (YEAR)	BP (PERCENTILE)	SYSTOLIC BP (mm HG) PERCENTILE OF HEIGHT							DIASTOLIC BP (mm HG) PERCENTILE OF HEIGHT						
		5th	10th	25th	50th	75th	90th	95th	5th	10th	25th	50th	75th	90th	95th
6	50th	91	92	93	94	96	97	98	54	54	55	56	56	57	58
	90th	104	105	106	108	109	110	111	68	68	69	70	70	71	72
	95th	108	109	110	111	113	114	115	72	72	73	74	74	75	76
	99th	115	116	117	119	120	121	122	80	80	80	81	82	83	83
7	50th	93	93	95	96	97	99	99	55	56	56	57	58	58	59
	90th	106	107	108	109	111	112	113	69	70	70	71	72	72	73
	95th	110	111	112	113	115	116	116	73	74	74	75	76	76	77
	99th	117	118	119	120	122	123	124	81	81	82	82	83	84	84
8	50th	95	95	96	98	99	100	101	57	57	57	58	59	60	60
	90th	108	109	110	111	113	114	114	71	71	71	72	73	74	74
	95th	112	112	114	115	116	118	118	75	75	75	76	77	78	78
	99th	119	120	121	122	123	125	125	82	82	83	83	84	85	86
9	50th	96	97	98	100	101	102	103	58	58	58	59	60	61	61
	90th	110	110	112	113	114	116	116	72	72	72	73	74	75	75
	95th	114	114	115	117	118	119	120	76	76	76	77	78	79	79
	99th	121	121	123	124	125	127	127	83	83	84	84	85	86	87
10	50th	98	99	100	102	103	104	105	59	59	59	60	61	62	62
	90th	112	112	114	115	116	118	118	73	73	73	74	75	76	76
	95th	116	116	117	119	120	121	122	77	77	77	78	79	80	80
	99th	123	123	125	126	127	129	129	84	84	85	86	86	87	88
11	50th	100	101	102	103	105	106	107	60	60	60	61	62	63	63
	90th	114	114	116	117	118	119	120	74	74	74	75	76	77	77
	95th	118	118	119	121	122	123	124	78	78	78	79	80	81	81
	99th	125	125	126	128	129	130	131	85	85	86	87	87	88	89
12	50th	102	103	104	105	107	108	109	61	61	61	62	63	64	64
	90th	116	116	117	119	120	121	122	75	75	75	76	77	78	78
	95th	119	120	121	123	124	125	126	79	79	79	80	81	82	82
	99th	127	127	128	130	131	132	133	86	86	87	88	88	89	90
13	50th	104	105	106	107	109	110	110	62	62	62	63	64	65	65
	90th	117	118	119	121	122	123	124	76	76	76	77	78	79	79
	95th	121	122	123	124	126	127	128	80	80	80	81	82	83	83
	99th	128	129	130	132	133	134	135	87	87	88	89	89	90	91
14	50th	106	106	107	109	110	111	112	63	63	63	64	65	66	66
	90th	119	120	121	122	124	125	125	77	77	77	78	79	80	80
	95th	123	123	125	126	127	129	129	81	81	81	82	83	84	84
	99th	130	131	132	133	135	136	136	88	88	89	90	90	91	92
15	50th	107	108	109	110	111	113	113	64	64	64	65	66	67	67
	90th	120	121	122	123	125	126	127	78	78	78	79	80	81	81
	95th	124	125	126	127	129	130	131	82	82	82	83	84	85	85
	99th	131	132	133	134	136	137	138	89	89	90	91	91	92	93
16	50th	108	108	110	111	112	114	114	64	64	65	66	66	67	68
	90th	121	122	123	124	126	127	128	78	78	79	80	81	81	82
	95th	125	126	127	128	130	131	132	82	82	83	84	85	85	86
	99th	132	133	134	135	137	138	139	90	90	90	91	92	93	93
17	50th	108	109	110	111	113	114	115	64	64	65	66	67	67	68
	90th	122	122	123	125	126	127	128	78	79	79	80	81	81	82
	95th	125	126	127	129	130	131	132	82	83	83	84	85	85	86
	99th	133	133	134	136	137	138	139	90	90	91	91	92	93	93

BP, blood pressure; *SD*, standard deviations.
[a]The 90th percentile is 1.28 SD, 95th percentile is 1.645 SD, and the 99th percentile is 2.326 SD over the mean.
From US Dept of Health and Human Services, National Institutes of Health, and National Heart, Lung and Blood Institute. *The Fourth Report on the Diagnosis, Evaluation, and Treatment of High Blood Pressure in Children and Adolescents*. National Institutes of Health publication 05-5267. Bethesda, MD: US Dept of Health and Human Services, National Institute of Health; 2005.

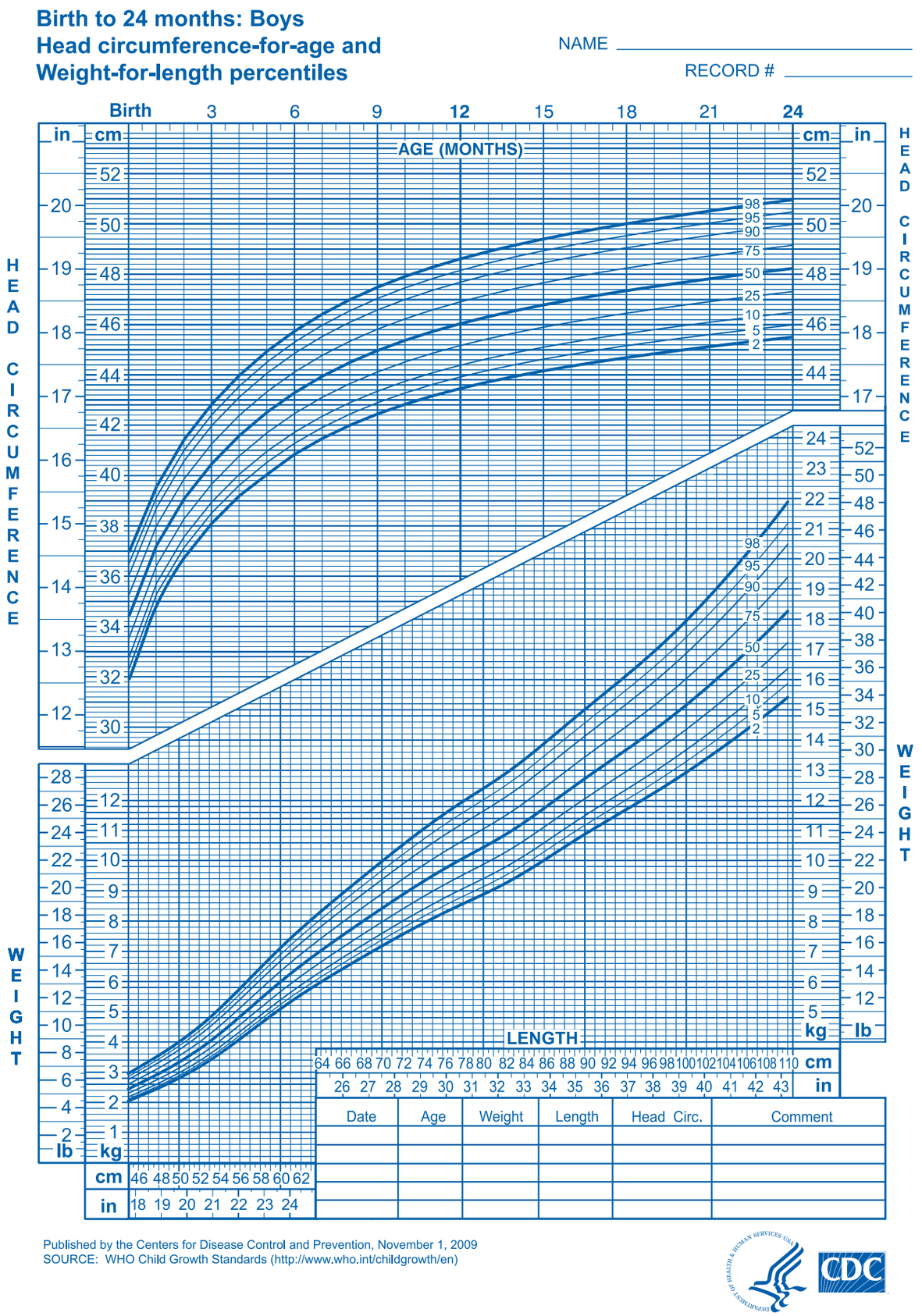

Figure 16-2 Head circumference and weight-for-length: boys.

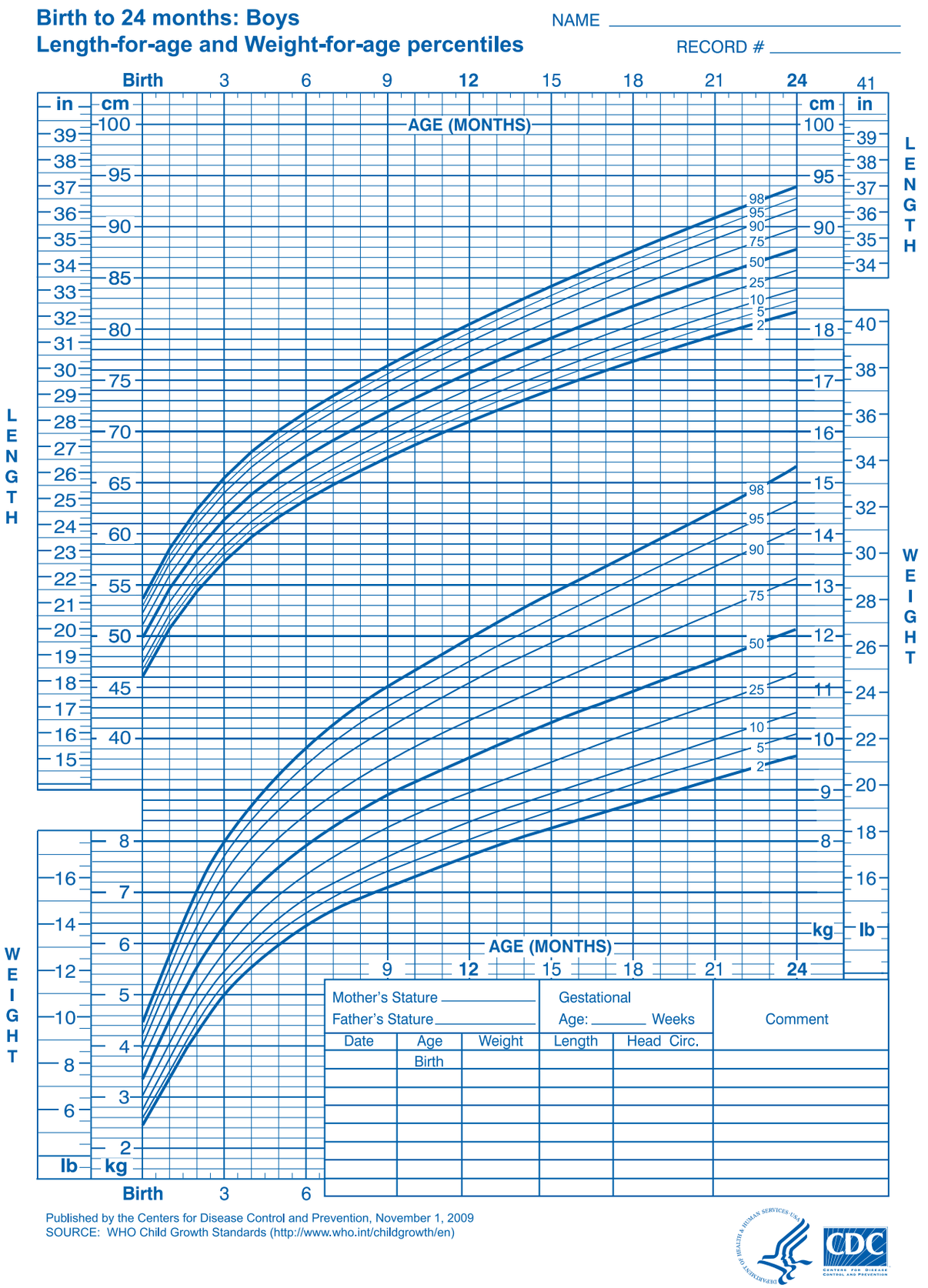

Figure 16-3 Length-for-age, weight-for-age: boys.

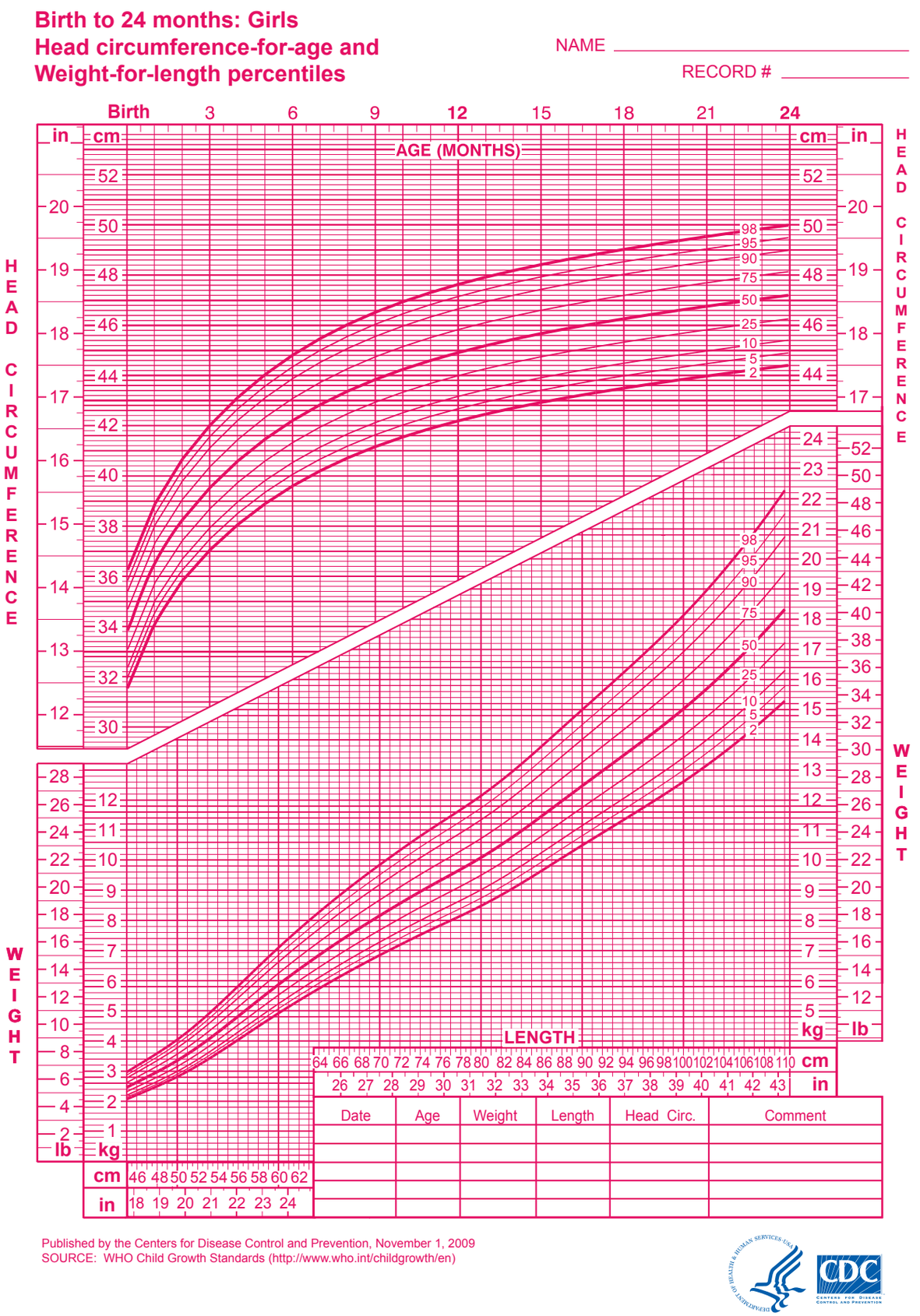

Figure 16-4 Head circumference and weight-for-length: girls.

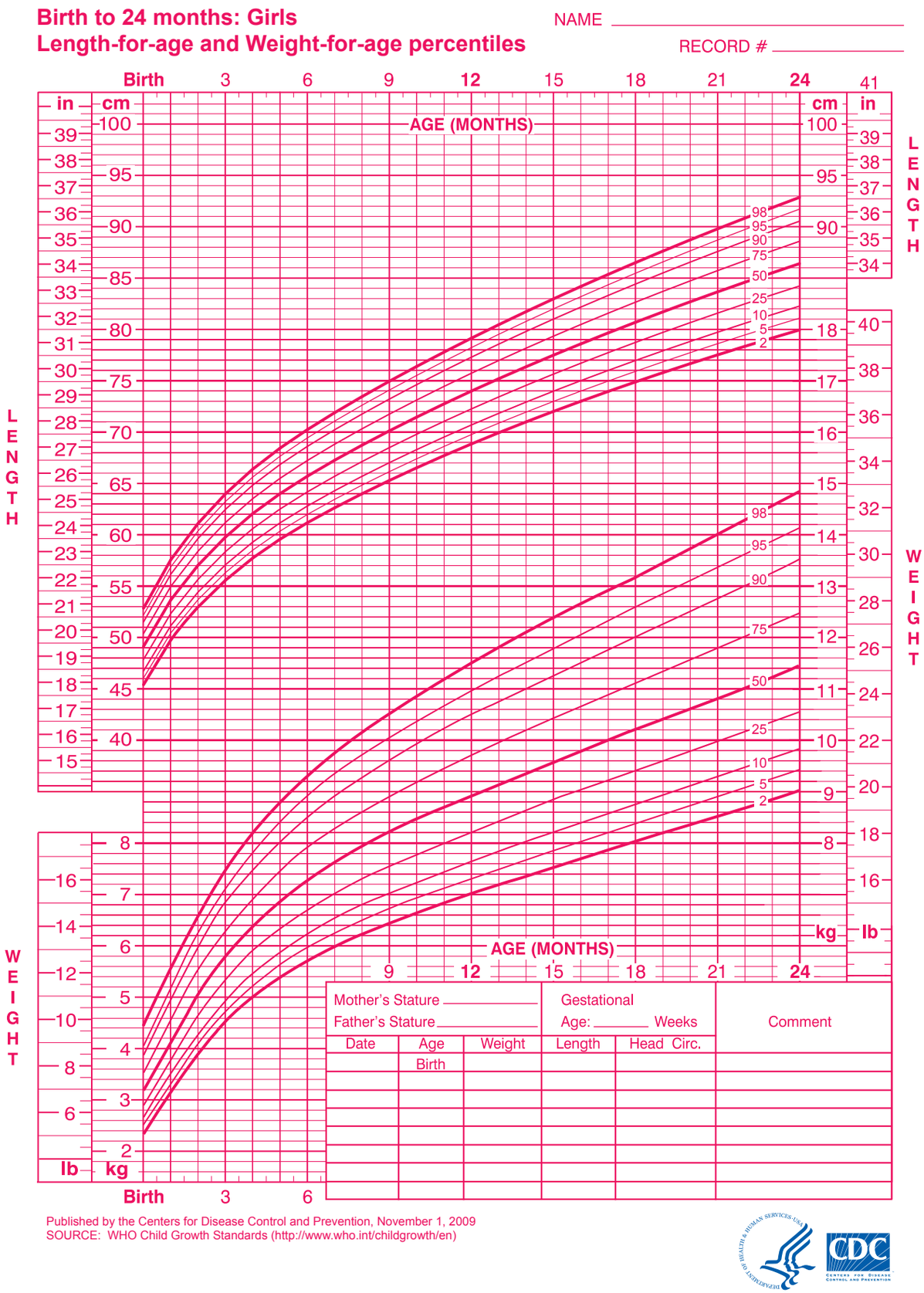

Figure 16-5 Length-for-age, weight-for-age: girls.

HEAD, EYES, EARS, NOSE, AND THROAT

Head

Examination of the head is important at all ages, but even more so in the newborn and young infant. Occipitofrontal head circumference, configuration, fontanels, and sutures are all important to evaluate. Head circumference should be related to standard charts for age (see Figure 16-2, Figure 16-4). Macrocephaly (large head) is associated with a prominent or wide forehead and large fontanels. Microcephaly (small head) is associated with a short, posterior recessed forehead and small fontanels. Frontal plagiocephaly presents as unilateral flattening of the forehead caused by premature closure of a coronal and sphenofrontal suture while occipital plagiocephaly is most often caused by prolonged positioning on the back in infancy. Scaphocephaly presents as a long skull with narrowing in the bitemporal diameter, and brachycephaly is a short skull in the anteroposterior dimension. The skull may be also flattened in the occiput; this most commonly occurs in infants with profound developmental delay or severe neuromuscular disease who cannot move their heads from side to side.

Fontanels reveal not only possible genetic and other disorders but give information about the internal cranial environment. A bulging fontanel indicates increased intracranial pressure. Normal closure of the posterior fontanel occurs between 1 and 3 months of age, and the anterior fontanel closes at approximately 18 months. Delayed closure may cause Down syndrome, hypothyroidism, or intrauterine growth restriction, and is also seen in the premature infant. Less commonly it may result from rickets, osteogenisis imperfecta, achondroplasia, and familial macrocephaly.

Abnormal skull configuration may be caused by premature closure of specific sutures. A sunken fontanel indicates reduced intracranial contents, whether tissue or fluid, and is most often associated with dehydration. The conditions associated with findings on the examination of the head are listed in Table 16-6.

Eyes

Findings during the eye examination include drooping eyelid, eyelid swelling, tearing, ocular misalignment, red eye, corneal clouding, "white pupil," papillary size difference, cataract, ocular swelling, and orbital swelling (allergy, infection, or trauma). A red reflex should always be evaluated during a neonatal and infant examination to rule out retinal lesions such as retinoblastoma.

Poor vision may be evaluated objectively in older children and adolescents in the office (see Chapter 28, Vision Screening, for specific vision screening tools and techniques for various age groups), but other than noting absent or reduced tracking, poor vision in an infant will need to be evaluated by a pediatric ophthalmologist. Conditions associated with these findings are listed in Table 16-6.

Ears

Common findings include those associated with examination of the auricle, ear canal, and middle ear. Low-set auricles are often associated with genetic syndromes. Inflammation of the auricle, including perichondritis involving the cartilaginous portion, is often associated with visible inflammation and pain on palpation. Trauma presents as ecchymoses or hematomas (occasionally with obvious bite marks). Displacement of the auricle away from the side of the head suggests mastoiditis. Otitis externa ("swimmer's ear") occurs because of infection resulting from persistent moisture with maceration or trauma from inserted objects. Canal edema, inflammation, and discharge are also common findings.

In the child with otitis externa with discharge, a foreign body should be suspected. Acute otitis media from eustacean tube dysfunction is also associated with pain. With spontaneous perforation of the tympanic membrane, pain resolves but discharge appears. Bloody discharge may be associated with basilar skull fracture. Hearing loss is both a sign and an elicited finding, defined as conductive or sensorineural. Congenital causes are usually sensorineural but may result from congentital malformation. Sensorineural hearing loss, often caused by genetic factors, can be quantified in the newborn period with the increasing use of otoacoustic emissions analysis. Acquired sensorineural hearing loss usually occurs over time from sonic trauma or drug toxicity. The cause of conductive hearing loss can often be found during the physical examination and includes canal atresia, foreign body, excessive cerumen, otitis externa, middle ear effusion, perforation of the tympanic membrane, cholesteotoma, and otosclerosis. Helpful tests include tympanography and pneumatoscopy. Since inserted ventilation tubes may affect these tests, the presence of tubes should be investigated during the examination of the tympanic membrane.

Nose

Findings commonly encountered during the physical examination of the nose include nasal obstruction, discharge, epistaxis, and nasal masses. Acute sinusitis is best diagnosed clinically, but when antibiotic treatment does not produce improvement, worsening of symptoms occurs, or there is suspected orbital involvement, imaging may be appropriate. Imaging may also be useful prior to referral to an ear, nose, and throat specialist for suspicion of chronic sinusitis as a cause of symptoms in conditions such as cystic fibrosis and others producing difficulty in mucus clearance. Acute nasal congestion is most often caused by allergy or viral infection. In the neonate, obstruction may be because of choanal atresia, leading to immediate feeding difficulty. Nasal foreign body should always be suspected in a child with unilateral, malodorous nasal discharge. Nasal polyps, although most commonly associated with chronic rhinitis, should always trigger a suspicion of cystic fibrosis, and epistaxis a consideration of clotting disorder. Common findings from the nose examination are summarized in Table 16-6.

Oropharynx and Throat

The most common findings in the oral examination include those associated with bacterial, viral, or fungal infection, although oral ulcers can be found in systemic diseases including Crohn disease, systemic lupus erythematosis, erythema multiforme, Behcet syndrome,

Table 16-6 Common Findings in the Head, Ears, Eyes, Nose, and Throat

SITE	FINDING	NEWBORN AND INFANT	CHILD	ADOLESCENT
Head	Large head (macrocephaly)	Familial, hydrocephalus, Beckwith-Weideman syndrome, Soto syndrome, Dandy-Walker syndrome, Arnold-Chiari malformation, cystic malformations, chromosomal disorders, chronic subdural hematoma, benign external hydrocephalus	Familial, hydrocephalus	Familial, hydrocephalus
	Small head (microcephaly)	Familial Intrauterine infection, maternal substance abuse, intrauterine CVA, chromosomal disorders	Familial, chromosomal disorders	Familial, chromosomal disorders
	Asymmetric head (plagiocephaly)	Prolonged back positioning, Intrauterine position, syndromic and nonsyndromic craniosynostosis	—	—
	Long head (scaphocephaly)	Premature sagittal suture fusion (syndromic and nonsyndromic craniosynostosis)	—	—
	Short head (brachycephaly)	Premature coronal suture fusion (syndromic and nonsyndromic craniosynostosis)	—	—
	Large fontanels	Macrocephaly because of hydrocephalus, craniosynostosis, osteogenesis imperfecta, achondroplasia, or hypothyroidism	—	—
	Small fontanels	Microcephaly, hyperthyroidism, malformation syndromes	—	—
	Bulging fontanels	Increased intracranial pressure	—	—
	Depressed fontanels	Dehydration, evolving cerebral atrophy	—	—
Eyes	Drooping eyelid (lid ptosis)	Congenital, Marcus-Gunn jaw winking, Horner syndrome, infant botulism	Congenital, myotonia, muscular dystrophy, myasthenia gravis, Horner syndrome, botulism	Same as child
	Lid swelling/ erythema	Hemangioma, infection, trauma	Trauma, infection, tumor, edema	Same as child
	Red eye	Infection, trauma (corneal injury), glaucoma	Infection, trauma, toxin, allergy, Kawasaki disease	Infection, trauma, toxin, allergy
	Irregular pupil, iritis, trauma	Infection, colobomata, Horner syndrome, CHARGE syndrome	Infection, head trauma, colobomata, trauma, iritis, Horner syndrome, tumor	Same as child
	White pupil (leukocoria)	Retinoblastoma, dystrophies, toxoplasmosis, cataract	Retinoblastoma, infection, retinal disease, cataract	Infection, retinal disease, cataract
	Cloudy cornea	Congenital glaucoma, trauma, congenital corneal dystrophy, Peters anomaly, keratitis	Glaucoma, trauma, corneal dystrophy, Peters anomaly, keratitis, metabolic disease, storage disease	Keratitis, chemical and infectious conjunctivitis
	Ocular misalignment	Strabismus	Strabismus, amblyopia	Same as child
	Tearing	Congenital nasolacrimal duct obstruction, congenital glaucoma, infection, corneal injury	Infectious or allergic conjunctivitis, foreign body, trauma, corneal injury	Same as child

Continued

Table 16-6 Common Findings in the Head, Ears, Eyes, Nose, and Throat—cont'd

SITE	FINDING	NEWBORN AND INFANT	CHILD	ADOLESCENT
Ears	**Auricle**			
	Low set	Genetic syndrome	Same	Same
	Swelling/ erythema	Cellulitis, perichondritis, insect bite, trauma, eczema, malformation	Cellulitis, perichondritis, impetigo, eczema, insect bite, trauma	Cellulitis, perchondritis, insect bite, trauma, infection
	Canal			
	Swelling/erythema	Furunculosis, trauma, foreign body	Furunculosis, trauma, infection, otitis externa, foreign body, CNS leak with head trauma (may occur with inserted ventilation tubes)	Same as child
	Discharge	Otitis externa		
	Middle ear			
	Swelling/erythema	Otitis media, bullous myringitis	Otitis media, cholesteatoma, bullous myringitis	Same as child
	Discharge	Otitis media with perforation of the tympanic membrane	Same as infant	Same as child
Nose	Mass	Hemangioma, nasolacrimal duct obstruction, trauma	Polyps, infection, foreign body, tumor	Same as child
	Discharge	Infection	Foreign body, infection, allergy, toxin	Infection, allergy, vasomotor rhinitis, toxin including drug abuse
	Bleeding (epistaxis)	Hemangioma, trauma, congenital vascular abnormality, local skin infection	Trauma, clotting disorder, thrombocytopenia, local skin infection, nasal perforation	Trauma, clotting disorder, thrombocytopenia, toxin including drug abuse (snorting), hypertension
	Obstruction	Mass, atresia, trauma	Trauma, mass, allergy	Trauma, mass, allergy, toxin
Oropharynx and throat	Eythema/ulcer/ exudate	Trauma, infection	Trauma, apthous ulcer, infection, erythema multiformae, peritonsillar abscess, Ludwig angina, retropharyngeal abscess, Kawasaki disease	Trauma, infection, Behcet syndrome, Crohn disease, erythema multiforme, systemic lupus erythematosis, peritonsillar abscess, Ludwig angina, GERD

CNS, central nervous system; *GERD,* gastroesophageal reflux disease.

and others. Pharyngitis, with or without tonsillar hypertrophy, is the most common abnormal finding. If throat pain is associated with stridor, dysphagia, or systemic toxicity, then severe infectious conditions should be suspected including epiglottitis, peritonsillar abscess, and retropharyngeal abscess. These conditions are best evaluated in an emergency department with full respiratory support capabilities. Evaluation and referral for tooth and gum disease should also accompany the oral examination (specifically reviewed in Chapter 40, Oral Health). These findings are outlined in Table 16-6.

CHEST WALL AND LUNGS

Assessing respiratory rate and respiratory effort, and following the sequence of inspection, palpation, and auscultation, will reveal findings associated with chest wall and lung dysfunction. Abnormalities of chest wall configuration include asymmetry, enlarged or diminished thoracic cage, and a prominent or inwardly displaced

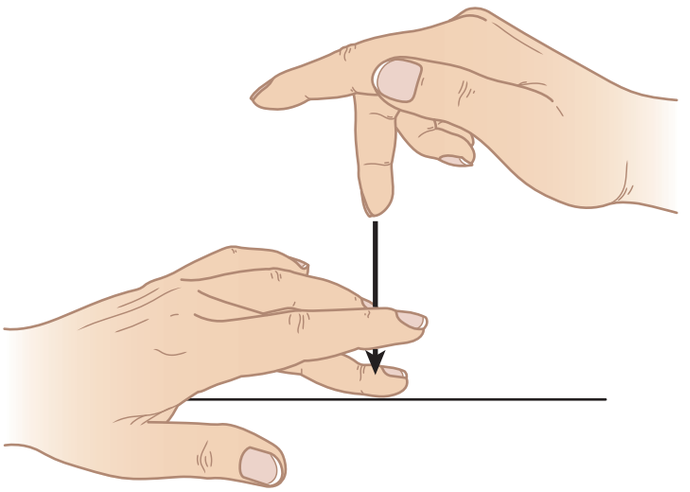

Figure 16-6 Technique of chest percussion.

sternum. Palpation of the chest wall may reveal masses or tenderness. Chest pain is not always of pulmonary origin. Findings are summarized in Table 16-3.

Palpation of the chest wall, along with percussion (Figure 16-6) can reveal much about the internal environment of the lung. Decreased vocal fremitus (vibrations) can be felt by placing the hands on the chest wall. Auscultation of the chest and upper airway yields respiratory sounds associated with various respiratory conditions. Wheezing is common and can be defined as monophonic and fixed, or polyphonic and dynamic. Stridor can be defined as inspiratory, expiratory, or both (biphasic). Cough can be described as wet (productive) or dry (nonproductive), paroxysmal and intermittent, or persistent, but is a sign and symptom, not specifically a finding. Other findings upon auscultation include rhonchi (coarse wet snaps and crackles) and rales (fine crackles). A summary of findings associated with abnormal lung sounds is found in Table 16-3.

Central cyanosis (best seen in the oral pharynx and nail beds) is a sign of serious disease representing significant desaturation of hemoglobin. Cyanosis and digital clubbing (Figure 16-7) are findings most often associated with cardiorespiratory disease but may also originate from other systems. Conditions associated with these findings are also listed in Table 16-3.

HEART AND PULSES

Inspection, palpation, and auscultation are the mainstays of eliciting findings related to the cardiovascular system. Most physicians begin with observation of the dynamic nature of the heart through examination of the chest wall and palpation at the left sternal border. The examination then progresses to ausculatory evaluation of the first and second heart sounds (S1 and S2) and the 4 valve sites (aortic, pulmonic, tricuspid, and bicuspid [mitral] areas) (Figure 16-8). Other heart sounds may also be documented during this examination. Findings of central cyanosis and digital clubbing (with chronic heart disease) should always place cardiovascular conditions in the differential diagnosis. Heart rate and rhythm are evaluated by auscultation and palpation of pulses. Pulses also indicate pathologic systemic and cardiovascular states. Decreased peripheral pulses are found in hypovolemia with hypotension, and in hypotension from other causes such as drugs, shock (thready pulse [ie, decreased pulse intensity with increased rate]), and aortic stenosis. Specifically, decreased leg pulses are found in coarctation of the aorta. Increased pulses are primarily found in hypertension but can also be associated with hyperthyroidism.

Pulsus paradoxicus is an exaggerated variation in the pulse rate with inspiration that is found in conditions involving airway obstruction (croup, bronchiolitis, asthma) but also with pericarditis, cardiac tamponade, and chronic sleep apnea.

The ausculatory examination is also essential to evaluate the heart sounds and timing, as well as the location, quality, and pitch of a murmur. A thrill felt over the precordium usually indicates a murmur with grading of at least 3/6 on the Levine scale. Systolic murmurs are described as holosystolic, systolic ejection, early systolic, midsystolic, or late systolic, whereas diastolic murmurs are described as protodiastolic, mid-diastolic, or late diastolic. Continuous murmurs are usually extracardiac. Pathologic murmurs require further evaluation through specialized testing and subspecialty evaluation to distinguish from functional (innocent) murmurs, especially with normal rhythms and lack of cyanosis. Functional or innocent murmurs are usually systolic ejection, virtually never holosystolic, and alter with change in position. They often have a musical or vibratory quality (Still murmur) and usually are noted between 6 months and 8 years of age. Common findings related to the heart and peripheral circulation are found in Table 16-7.

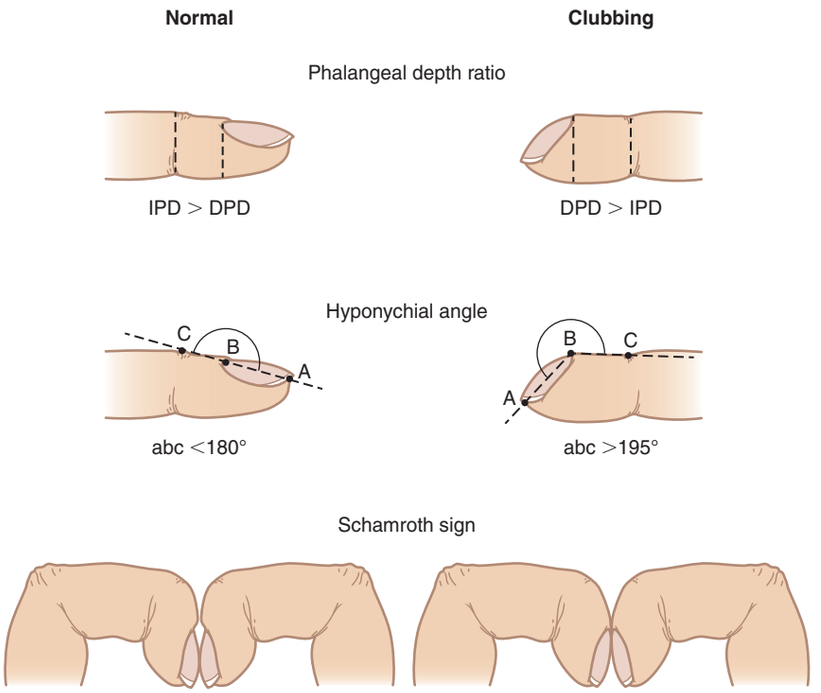

Figure 16-7 Clubbing and Schamroth sign. Clubbing can be measured by comparing the distal phalangeal diameter (DPD) to the interphalangeal diameter (IPD), which is less than 1 in normal subjects. The hyponychial angle is increased in clubbing, and the normal diamond-shaped opening when opposite fingers are opposed disappears with clubbing (Schamroth sign). *(Adapted from Pasterkamp H. The history and physical examination. In: Wilmott RW, Boat TF, Bush A, et al, eds.* Kendig and Chernick's Disorders of the Respiratory Tract in Children. *8th ed. Philadelphia, PA: Elsevier Saunders; 2012: 127, with permission from Elseiver.)*

GASTROINTESTINAL

Inspection, auscultation, percussion, and palpation (usually in that order) elicit findings in the gastrointestinal tract. Findings on inspection include abdominal distention, scaphoid abdomen, and occasionally abdominal mass. In a newborn, a scaphoid abdomen associated with respiratory distress indicates congenital diaphragmatic hernia, but in an older child can occur as a result of abdominal trauma with diaphragmatic rupture. A flat or scaphoid abdomen may also occur in malnutrition (without ascites) and protuberant abdomen with neuromuscular disease. Abdominal distention may be caused by air, fluid, or masses.

Auscultation for bowel sounds may reveal their absence, hypoactivity, or hyperactivity.

Bowel sounds can be absent in peritonitis or with bowel obstruction. Hypoactive sounds occur with local ileus and obstruction, as may occur in distal intestinal obstruction syndrome (DIOS) in children and adolescents with cystic fibrosis. Hyperactive bowel sounds are most often found with gastroenteritis, but also with malabsorption. Current medication use must also be considered when evaluating bowel sounds.

Percussion may elicit tympany, which indicates gas accumulation (intra- or extraintestinal) and may be a clue as to the location of underlying fluid in ascites. Percussion with palpation will define the location and degree of ascites by evaluating the patient for shifting dullness and a fluid wave (Figure 16-9). Dullness on percussion, as in the thoracic examination, is caused by fluid or a solid mass.

Palpation will specifically elicit pain as well as abnormal abdominal contents. Rebound tenderness (pain on sudden release of palpating fingers) is found with underlying peritoneal irritation. Pain elicited in a specific location gives clues as to the underlying diagnosis (Figure 16-10). Masses can often be localized through 1- or 2-handed ballottement, which will also distinguish enlarged intra-abdominal organs (Figure 16-11). Localizing a mass through palpation and ballottement and taking into account a child's age and sex gives clues as to its cause (Figure 16-12). Conditions associated with specific findings on the abdominal examination are found in Table 16-8.

MUSCULOSKELETAL

Inspection and palpation with manipulation are the prime methods of eliciting findings related to the musculoskeletal system. Observation of gait and use of limbs, measuring strength, and establishing range of motion are also essential to the physical examination of this system. This part of the examination overlaps with neurology, which is discussed in full in the following section.

Findings associated with musculoskeletal dysfunction include not moving a limb, limb abnormality, limp, abnormal head shape or size (covered in the head, eyes, ears, nose, and throat section and

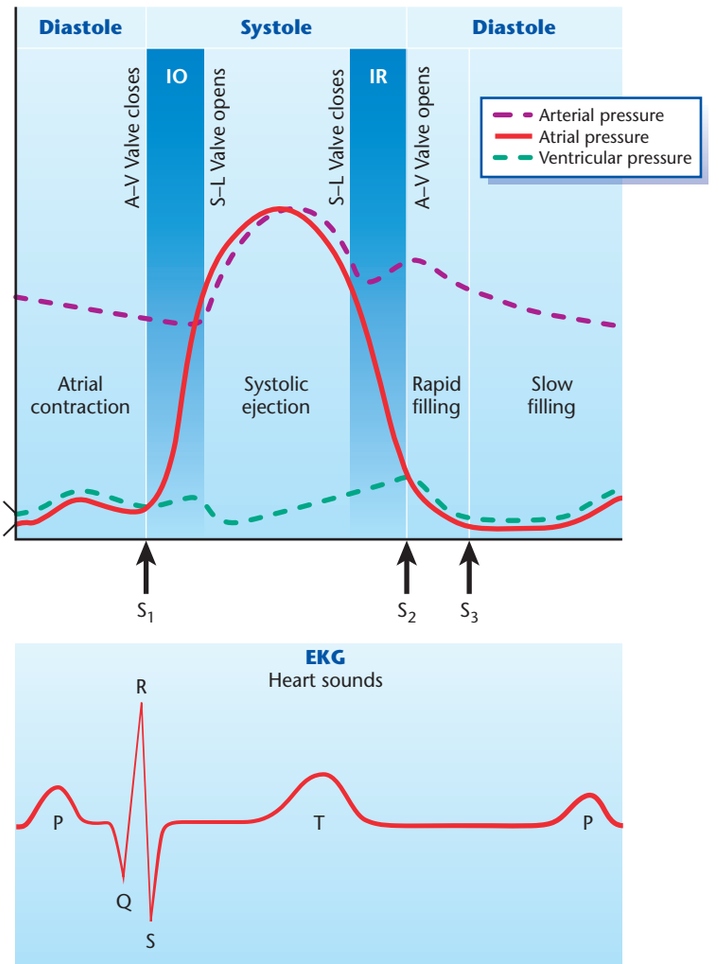

Figure 16-8 The cardiac cycle and heart sounds.

Table 16-7 Common Findings in the Heart and Circulation

SITE	FINDING	NEWBORN AND INFANT	CHILD	ADOLESCENT
Heart	Thrill	>3/6 on the Levine scale	Same as infant	Same as child
	S2 fixed wide split	ASD	ASD	ASD
	S3 gallop	CHF	Same as infant	Same as child
	Systolic murmurs	Normal (functional, transition), *Ejection*: ventricular outflow abnormalities, aortic/pulmonic valve stenosis, VSD, A-V canal	Same as infant, but also consider mitral regurgitation, coarctation	Same as child, but functional murmurs rare
	Diastolic murmurs	A-V valve insufficiency	Same as infant, but also consider mitral stenosis	Same as child
	Continuous murmurs	Patent ductus arteriosus	Venous hum	Supraclavicular innocent murmur
	Systolic ejection clicks	Aortic/pulmonic valve stenosis, mitral/tricuspid prolapse (midsystolic), coarctation of the aorta	Same as infant	Same as child

Continued

Table 16-7 Common Findings in the Heart and Circulation—cont'd

SITE	FINDING	NEWBORN AND INFANT	CHILD	ADOLESCENT
Pulses	Diminished leg pulses	Coarctation of the aorta, hypoplastic left heart syndrome, decreased cardiac output, hypotension	Coarctation of the aorta, vascular obstruction (eg, embolus), decreased cardiac output, hypotension	Same as child
	Diminished peripheral intensity	Hypovolemia/ hypotension, shock (thready), aortic stenosis, cardiac tamponade, drugs	Same as infant	Same as child
	Increased peripheral intensity	Hypertension, hyperthyroidism, drugs	Same as infant	Same as child
	Pulsus paradoxicus	Asthma, bronchiolitis, croup (airway obstruction)	Asthma, pericarditis, cardiac tamponade, sleep apnea	Same as child

ASD, atrial septal defect; *A-V*, atrioventricular; *CHF*, congestive heart failure; *VSD*, ventricular septal defect.

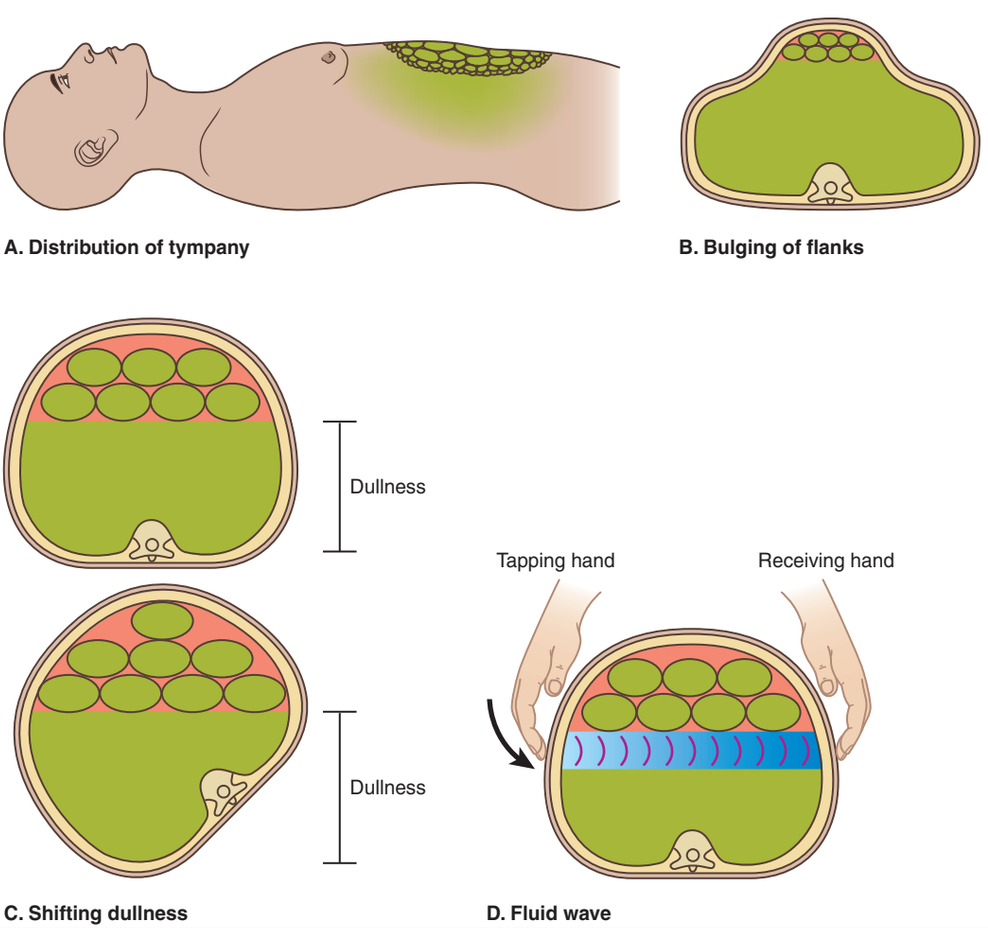

Figure 16-9 Signs of ascites. (*Adapted from LeBlond RF, DeGowin RL, Brown DD. The abdomen. In:* DeGowin's Diagnostic Examination. *8th ed. New York, NY: McGraw-Hill; 2004.*)

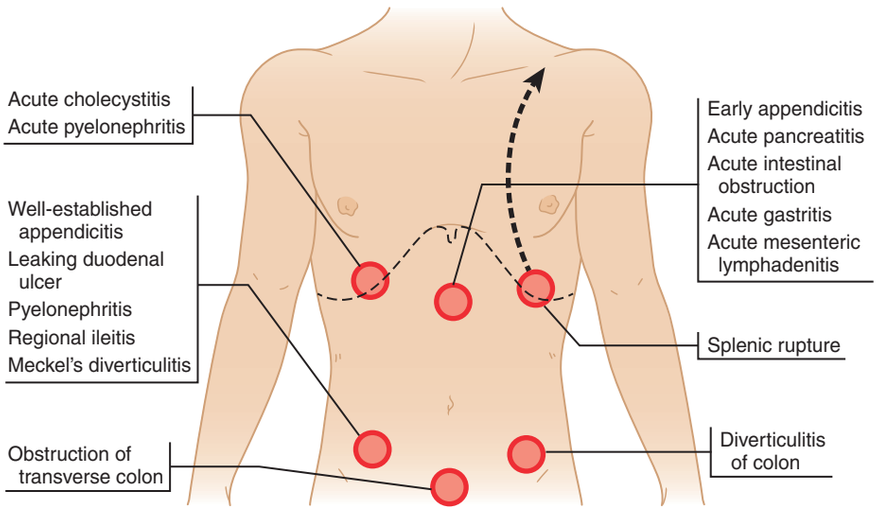

Figure 16-10 Common location of acute abdominal pain. (*Adapted from LeBlond RF, DeGowin RL, Brown DD. The abdomen. In:* DeGowin's Diagnostic Examination. *8th ed. New York, NY: McGraw-Hill; 2004.*)

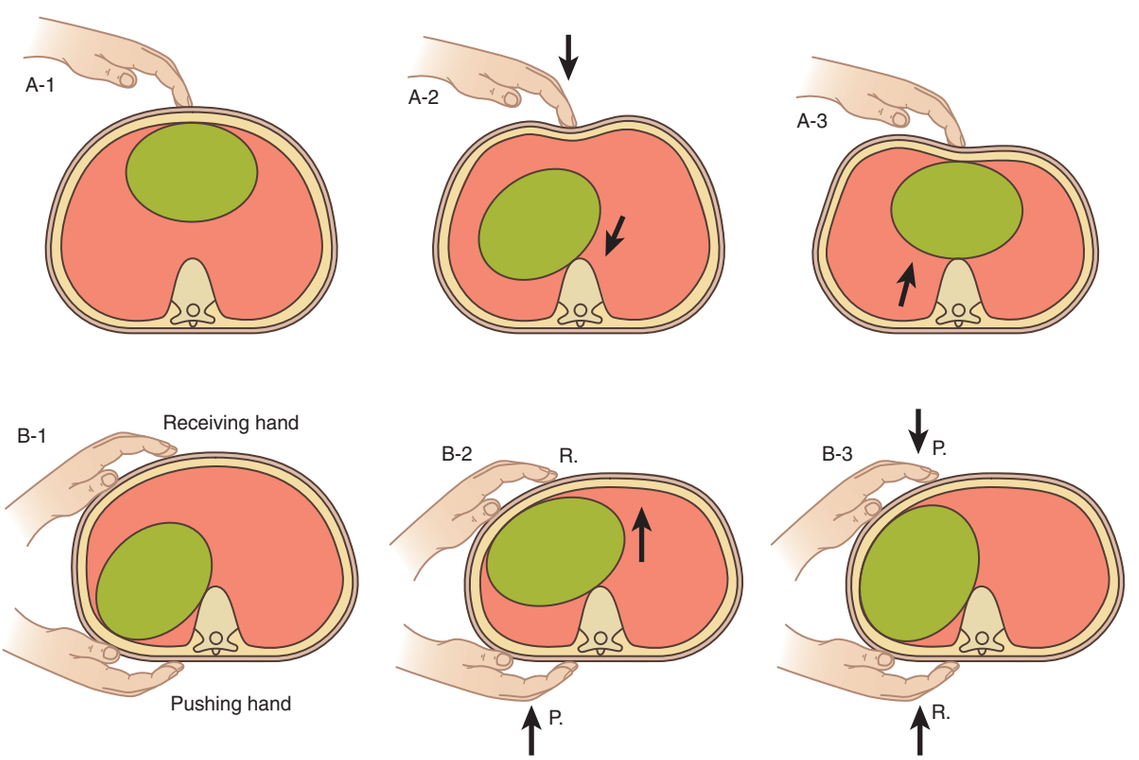

Figure 16-11 Ballottement of abdominal masses. **A**. One-hand ballottement. The fingers are plunged into the abdomen and held there; a freely moveable mass will rebound upward and be felt with the fingers. **B**. Bimanual ballottement. Used to determine the size of a large abdominal mass. One hand (P) pushes the posterior abdominal wall, while the other (R) palpates the anterior abdomen. The thickness of the mass may be determined between the two hands. (*Adapted from LeBlond RF, DeGowin RL, Brown DD. The abdomen. In:* DeGowin's Diagnostic Examination. *8th ed. New York, NY: McGraw-Hill; 2004.*)

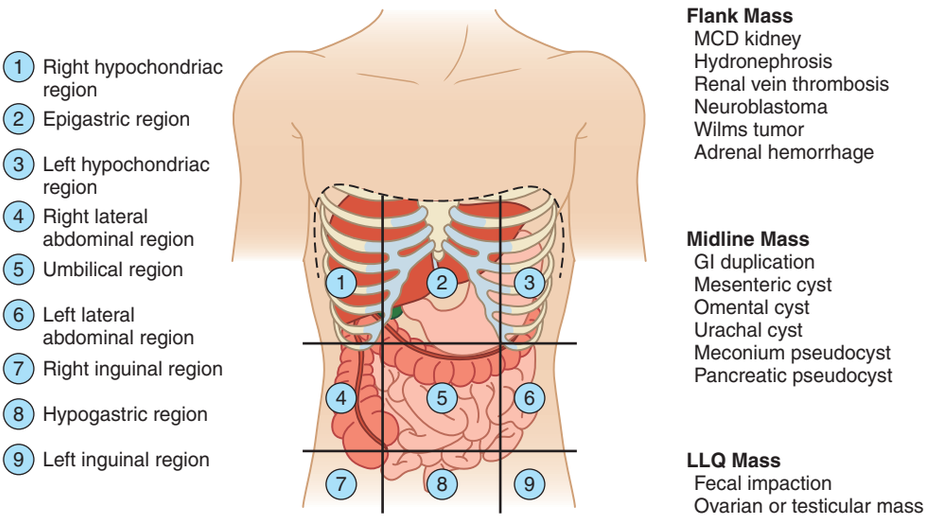

Figure 16-12 Location of abdominal masses by anatomic regions.

Table 16-8 Common Findings in the Gastrointestinal Tract

SITE	FINDING	NEWBORN AND INFANT	CHILD	ADOLESCENT
Abdomen	Flat or scaphoid	Congenital diaphragmatic hernia, diaphragmatic paresis, paralysis, malnutrition	Traumatic diaphragmatic hernia, malnutrition	Same as child
	Distended	Intestinal obstruction (volvulus, intussusception, meconium ileus, rectal or anal stenosis, etc), ascites (hypoproteinemia from liver disease, renal disease, malabsorption), urinary retention, hepatosplenomegaly, tumor, and constipation	Intestinal obstruction (tumor, intussusception, polyps, DIOS), ascites from liver disease, renal disease, malabsorption, peritonitis, tumor, hepatosplenomegaly, and constipation	Same as child, consider pregnancy
	Pain	Pain is difficult to elicit in an infant; consider peritonitis, malrotation/volvulus, appendicitis, sickle cell disease, incarcerated hernia, Hirschsprung disease, gastroenteritis, UTI, pneumonia, trauma	Constipation, Hirschsprung disease, sickle cell disease, incarcerated hernia, peritonitis, appendicitis, GERD, UTI, pneumonia, trauma, abscess	Same as child but consider pregnancy (including tubal) and irritable bowel syndrome
	Mass	Enlarged liver or spleen, hydronephrosis, tumor, intussusception, pyloric stenosis, fecal impaction, cysts, incarcerated hernia	Enlarged liver or spleen, hydronephrosis, fecal impaction, DIOS, tumor, incarcerated hernia, cysts, renal vein thrombosis, adrenal hemorrhage	Same as child but consider pregnancy and ovarian masses
	Hypoactive bowel sounds	Peritonitis/sepsis, gastroenteritis with local ileus, drugs, hypokalemia	Peritonitis, obstruction, ileus, trauma, drugs, hypokalemia, fecal impaction	Same as child
	Hyperactive bowel sounds	Manual manipulation of the abdomen, malabsorption, gastroenteritis, diarrhea, drugs	Same as infant but consider Crohn disease and ulcerative colitis, enterocolitis, drugs	Same as child

DIOS, distal intestinal obstruction syndrome; *GERD,* gastrointestinal reflux disease; *UTI,* urinary tract infection.

Table 16-6), joint pain or swelling, curved spine, chest wall abnormalities (covered in the chest wall and lungs section and Table 16-3), stiffness of muscles and joints, hip instability, and foot abnormalities. An observation of symmetry is an important part of the musculoskeletal evaluation.

When an infant will not move a limb, the physician should always suspect trauma (accidental or intentional), any painful condition of the bones or joints, or muscle weakness. Fracture of the clavicle (with swelling and tenderness and sometimes crepitus), humeral fracture, or brachial plexus injury can occur with birth trauma, and results in the limited use of an arm. Increased muscle tone in a child after 1 year of age may suggest cerebral palsy (CP). Osteomyelitis of any bone, including the humerus, and septic arthritis of a joint will lead to reduced use of the corresponding limb (pseudoparalysis). Clavicular fracture and upper and lower extremity fractures with pain, swelling, and decreased use of the affected limb are also common sports injuries in children and adolescents. Atraumatic swelling of a joint, with or without systemic symptoms, always requires further investigation and is a finding with both infectious and collagen vascular disease etiologies. These occur most often in older children and teens. Developmental dysplasia of the hip occurs in infants and limits leg motion, as does aseptic necrosis of the head of the femur in older children (Legg-Calvé-Perthes disease) Likewise, atraumatic, localized swelling and tenderness of a lower extremity in an older child or adolescent should prompt a workup for infection (including osteomyelitis) and neoplasm (including osteogenic sarcoma and Ewing sarcoma). Swelling and tenderness over the tibial tuberosity is a finding in Osgood-Schlatter disease.

Scoliosis is common in children with neuromuscular disease but does occur progressively in otherwise normal children and adolescents. The back examination is an essential part of the physical examination at all ages, and scoliosis or kyphosis should be further monitored or evaluated. Other congenital anomalies may accompany scoliosis, including those of the bladder, kidneys, or heart, as well as hearing disorders. Kyphosis may be progressive and can result in paraplegia.

By age 7, most children have lost the wide-based, short-step gait of the younger child and have adopted the typical adult gait. Atypical gaits include reduced time in the stance phase of the gait cycle (limp) because of pain, lurching and a wide-based gait because of muscle weakness from any cause, circumduction (Trendelenburg gait) caused by neuromuscular disease, and the scissors gait of diplegic or quadriplegic CP. Genu varum (foot inturning) is not uncommon at all ages, but when severe it may lead to gait disturbance.

Examination of the hands and feet may reveal abnormalities sometimes associated with other congenital anomalies. Polydactyly and syndactyly are associated with multiple genetic syndromes. Joint contractures occur in arthrogryposis multiplex congenita. Foot findings in infants include metatarsus adductus and talipes equinovarus (clubfoot) among others. Finding of a rigid cavus (exaggerated medial longitudinal arch) suggests CP, myelomeningocele, or hereditary sensorimotor neuropathies.

Findings in the feet of older children and adolescents include pes planus or pes cavus deformities, bunion, ingrown nail, and a variety of toe deformities. Musculoskeletal findings are summarized in Table 16-9, but are also addressed in Table 16-6 and Table 16-10.

Table 16-9 Common Findings in the Musculoskeletal System

SITE	FINDING	NEWBORN AND INFANT	CHILD	ADOLESCENT
Upper limb	Not moving	Clavicular fracture, brachial plexus injury, Erb or Klumpke palsy, limb fracture or contusion, septic joint, contractures, osteomyelitis, spinal cord injury, pain (consider child abuse)	Clavicular fracture, contusion, fracture, joint swelling (infection, arthritis), osteomyelitis, contractures, dislocation, subluxation, tumor, pain (consider child abuse)	Same as child, but also consider cystic fibrosis osteoarthropathy
	Swelling	Contusion, fracture, septic joint, osteomyelitis, edema, lymphoma, hemangioma, infection	Same as infant, but consider rheumatic disease, Lyme arthritis, synovitis, sickle cell arthropathy, tumor	Same as child
	Erythema	Septic arthritis, osteomyelitis, cellulitis, ecchymoses, infection, fat necrosis	Same as infant, but also consider rheumatic disease	Same as child, but also consider muscle injury
Lower limb	Not moving	Hip dysplasia, septic joint, contractures, osteomyelitis, meningomyelocele	Aseptic necrosis, septic joint, osteomyelitis, viral synovitis, contusion, fracture, arthritis	Contusion, fracture, septic joint, viral synovitis, osteomyelitis, arthritis
	Swelling	Septic joint, osteomyelitis, contusion, fracture, edema, lymphoma, hemangioma, skin and tissue infection	Same as infant, but also consider collagen vascular disease and tumor, Osgood-Schlatter disease	Same as child but also consider deep vein thrombosis, ruptured Baker cyst (pseudothrombosis)

Continued

Table 16-9 Common Findings in the Musculoskeletal System—cont'd

SITE	FINDING	NEWBORN AND INFANT	CHILD	ADOLESCENT
	Erythema	Septic arthritis, osteomyelitis, cellulitis, ecchymoses, skin and tissue infeciton	Same as infant, but also consider collagen vascular disease, Lyme arthritis, synovitis, sickle cell arthropathy, tumor	Same as child
Back	Scoliosis–lateral curve	Congenital, vertebral anomaly, neuromuscular disease, pain, tumor	Same as infant, congenital, idiopathic, neuromuscular disease, Scheurermann kyphoscoliosis	Same as child
	Kyphosis–anterior-posterior curve	Congenital, neuromuscular disease	Congenital, idiopathic, postural, neuromuscular disease, Scheuermann's kyphosis/kyphoscoliosis, osteogenesis imperfecta, bone dysplasias	Same as child
Gait	Wide-based	Normal	Neuromuscular disease, ataxia	Same as child
	Limp, antalgic	Pain in lower extremity from any cause, hip dysplasia	Pain in lower extremity from any cause, aseptic necrosis of the femur, vertebral abnormality with neuropathy	Same as child, but also consider slipped femoral capital epiphysis
	Hip drop, circumducting gait, Trendelenburg gait	Rare	Neuromuscular disease, rheumatic disease, hip disease	Same as child
	Scissoring	Cerebral palsy	Cerebral palsy	Cerebral palsy
Hand	Web fingers, syndactyly	Incidental anomaly, genetic syndrome (Apert, Carpenter, de Lange, Laurence-Moon-Biedl, etc)	Same as infant	Same as infant
	Multiple digits, polydactyly	Incidental anomaly, genetic syndrome (Carpenter, Ellis-van Creveld, Meckel-Gruber, Orofacial digital syndrome, etc)	Same as infant	Same as infant
Feet	Syndactyly, polydactyly	May have similar hand anomalies, occurs in genetic and chromosomal syndromes	Same as infant	Same as infant
	Foot turns in	Congenital metatarsus adductus, contracture, tibial torsion, femoral anteversion, club foot (talipes equivovarus)	Congenital metatarsus adductus, contracture, tibial torsion, femoral anteversion	Same as child
	Foot turns out	Physiologic until age 18 months, congenital, contracture	Congenital (external tibial torsion), flat foot	Same as child
	Flat foot (pes planus)	Congenital (may be normal)	Same as infant	Same as infant
	High arch (pes cavus)	Congenital, exaggerated and rigid in cerebral palsy, myelomeningocele, hereditary sensorimotor neuropathies	Same as infant	Same as infant
	Round bottom, rocker bottom foot, congenital vertical talus	Congenital, genetic and chromosomal syndromes	Same as infant	Same as infant

Table 16-10 Common Neurologic Findings

SITE	FINDING	NEWBORN AND INFANT	CHILD	ADOLESCENT
Systemic	Altered consciousness, agitation, disorientation, lethargy, coma	CNS malformations, hydrocephalus, infection, glucose, calcium, and electrolyte abnormalities, inborn errors of metabolism, hypothyroidism, hypoadrenalism, trauma, hypoxia, hypercarbia, ingestion	Ingestion, toxins, infection, hypoglycemia, ketoacidosis, Reye syndrome, Lyme disease, encephalopathy, hypertension, electrolyte abnormality, trauma, tumor, hypoxia	Same as child; toxic ingestion or other self-administration, syncope, and hyperventilation become more common
	Developmental delay, regression	Genetic or chromosomal syndrome, hypothyroidism, infection, prenatal or neonatal hypoxia, trauma, hydrocephalus, metabolic disease, sensory deprivation	Same as infant, but also consider neurofibromatosis, tuberous sclerosis, tumor, heavy metal poisoning	Same as child
	Generalized decreased tone (hypotonia)	Genetic or chromosomal syndrome, oculocerebral renal syndrome, renal tubular acidosis, familial dysautonomia, metabolic myopathies, storage diseases, mitochondrial disorders, spinal muscular atrophy, infection, botulism, congenital myasthenia gravis	Genetic or chromosomal syndrome, spinal muscular atrophy, muscular dystrophies, storage disease, infection, Guillain-Barré syndrome, tumor, heavy metal exposure, uremia, drugs, spinal cord injury, myopathies, myasthenia gravis	Same as child, but also consider intentional toxic ingestion and psychosomatic disorder
	Generalized increased tone (hypertonia)	Genetic or chromosomal syndrome, prenatal or perinatal hypoxia leading to cerebral palsy, seizure disorder	Genetic or chromosomal syndrome, cerebral palsy, seizure disorder	Same as child
	Clumsiness (ataxia) See also gait disturbance (Table 16-9)	Hereditary, cerebellar aplasia, Chiari malformation, Dandy-Walker malformation, infection, postinfection, heavy metal toxicity, inborn errors of metabolism, mitochondrial disorders, trauma, tumor, AVM, stroke	Same as infant, but consider toxic ingestion vasculitis, and metastases from a primary tumor, rheumatic/vasculitic disorders, cerebellar disorders	Same as child, but trauma and toxic ingestion become more likely
	Seizures	See Chapter 327, Seizure Disorders	See Chapter 327, Seizure Disorders	See Chapter 327, Seizure Disorders
Focal	Facial asymmetry	Facial nerve or muscle aplasia (Möbius syndrome), tumor	Congenital, Bell palsy, herpes zoster, tumor, Lyme disease	Same as child
	Weakness on 1 side (hemiplegia)	AVM, arachnoid cyst, Chiari malformation, trauma, tumor, stroke (hemorrhagic or hypercoaguable states)	Same as infant, but consider cerebral abscess, viral myelitis, osteomyelitis, sarcoidosis, stroke	Same as child
	Weakness of both legs (paraplegia)	AVM, spina bifida, myelomeningocele arachnoid cyst, Chiari malformation, trauma, tumor, stroke (hemorrhagic or hypercoagulable states), osteopetrosis, mitochondrial disorders	Same as infant, but also consider cerebral abscess, viral myelitis, vertebral fracture, vertebral osteomyelitis, spinal TB, sarcoidosis, muscular dystrophy, demyelinating disease, primary tumor metastases	Same as child, but trauma becomes more likely

Continued

Table 16-10 Common Neurologic Findings—cont'd

SITE	FINDING	NEWBORN AND INFANT	CHILD	ADOLESCENT
	Weakness of all 4 extremities (quadriplegia)	AVM, spina bifida, tethered cord, arachnoid cyst, Chiari malformation, trauma, tumor, stroke (hemorrhagic or hypercoagulable states), osteopetrosis, atlantoaxial dislocation, mitochondrial disorders, spinal muscular atrophy type 1, botulism, hypokalemia, congenital myasthenia gravis	Same as infant, but also consider viral myelitis, vertebral fracture, vertebral osteomyelitis, sarcoidosis, muscular dystrophy, spinal muscular atrophy type 2 and type 3, demyelinating disease, primary tumor metastases	Same as child, but trauma becomes more likely
	Not moving a limb	See Table 16-9	See Table 16-9	See Table 16-9

AVM, atriovenous malformation; *CNS,* central nervous system; *TB,* tuberculosis.

NEUROLOGY

As mentioned above, findings on the musculoskeletal examination may indicate neurologic disorders. Therefore, the musculoskeletal and neurologic examinations complement each other in the search for the primary cause of a specific finding. In addition, knowledge of appropriate developmental milestones in relation to musculoskeletal and neurologic maturity will help the physician determine whether a child is experiencing developmental delay or regression, which may have many causes, including degenerative muscle or neurologic disease and even social deprivation. Occasionally a child will present to the physician with a seizure, and multiple etiologies must be considered with this finding.

Common findings encountered on the neurologic examination include altered consciousness, developmental delay/regression, focal weakness, generalized weakness, hypotonia, ataxia, hypertonia (spasticity), hypo- and hyperreflexia, decreased and increased sensation, movement disorders, and, rarely, seizures (although a history of suspected or known seizures may be the reason for the evaluation).

Altered levels of consciousness can vary from disorientation to lethargy to unconsciousness. In an infant, secondary effects of drugs, disorders of electrolyte metabolism, inborn errors of metabolism, hypoglycemia, infection, and trauma should be considered. Intracranial or brainstem tumors must also be considered, especially with focal findings such as weakness. The Glasgow Coma Scale (Table 16-11) is useful to quantify and communicate the level of consciousness.

The finding of developmental delay can be the result of many causes including environmental (such as birth injury), infection, toxic exposure, and genetic etiologies.

However, social deprivation, malnutrition, chromosomal syndromes, and hypothyroidism must also be considered. Regression from previous milestones is always cause for concern and should suggest a genetic or metabolic syndrome. Sudden social deprivation may also lead to regression. The finding of focal weakness may be caused by a musculoskeletal condition but may also be a result of a neurologic disorder, either of the peripheral or central nervous system. Hand preference in children younger than 2 years of age or a change in hand preference in older children should always prompt an investigation for musculoskeletal or neurologic causes. A general knowledge of specific innervations of body regions is helpful when categorizing this finding. Generalized weakness, if chronic, is most likely because of neuromuscular disease, but when acute, it may be attributed to many causes (eg, infant botulism, Guillain-Barré). Hypertonia and hypotonia have many causes, which, if chronic, need to be evaluated by a pediatric neurologist. Acute causes include drug ingestion, electrolyte disturbance, and trauma, among others. The finding of ataxia has multiple acute and chronic causes, and usually presents as gait disturbance. As with problems of muscle tone, drug ingestion, acute metabolic disturbance, and infection may be immediate issues, whereas cerebella dysfunction because of tumor, malformation, or bleeding may lead to more chronic problems. Hypo- and hyperreflexia are findings in both acute and chronic neurologic and metabolic disease, although a great deal of variability in deep tendon reflexes is seen in normal individuals. Asymmetry in tone, reflexes, strength, and sensation suggests a focal abnormality. Involuntary movement disorders stem from a variety of causes that include toxic, metabolic, infectious, vascular, and traumatic. Recognizing the pattern of the disorder can often help in determining the cause. The pattern of a seizure disorder is also important to recognize. True seizures, although always neurologic in origin, may be triggered by non-neurologic disorders, such as hypoglycemia or hyponatremia. A comprehensive discussion of seizure patterns and etiologies appears in Chapter 327, Seizure Disorders. Other than simple febrile seizures, seizure disorders should be evaluated by a child neurologist.

Findings from the neurologic examination are found in Table 16-10.

Table 16-11 Glasgow Coma Scale

EYE-OPENING RESPONSE

SCORE	>1 YEAR	<1 YEAR
4	Spontaneous	Spontaneous
3	To verbal command	To shout
2	To pain	To pain
1	None	None

MOTOR RESPONSE

SCORE	>1 YEAR	<1 YEAR
6	Obeys commands	Spontaneous response
5	Localizes pain	Localizes pain
4	Withdraws from pain	Withdraws from pain
3	Displays abnormal flexion to pain (decorticate rigidity)	Displays abnormal flexion to pain (decorticate rigidty)
2	Displays abnormal extension to pain (decerebrate rigidty)	Displays abnormal extension to pain (decerebrate rigidty)
1	None	None

VERBAL RESPONSE

SCORE	>5 YEARS	2–5 YEARS	0–23 MONTHS
5	Is oriented and converses	Uses appropriate words and phrases	Babbles, coos appropriately
4	Conversation is confused	Use inappropriate words	Cries but is consolable
3	Words are inappropriate	Cries or screams persistently to pain	Cries or screams persistently to pain
2	Sounds are incomprehensible	Grunts or moans to pain	Grunts or moans to pain
1	None	None	None

The Glasgow Coma Scale score is the sum of best eye-opening, motor, and verbal responses. Scores range from 3 to 15. Severe indicates a score of <9; moderate, 9–12; and mild, 13–15.

INTEGUMENT

The integumentary system consists of skin, hair, and nails. Conditions associated with this system may be limited to a specific structure or may be a manifestation of a systemic disease. Therefore, knowledge of the findings associated with systemic disease is important, and a complete review of systems, history, and physical examination should be performed as indicated. Observation and palpation are the most useful components of the specific integument examination. Common findings of skin lesions are listed in Box 16-1. Any of these lesions may be associated with erythema depending on the etiology. The color of macules (red, blue, purple, hypo- or hyperpigmented, depigmented) will often indicate the likely cause (Table 16-12).

Common findings associated with examination of the hair include hair loss (alopecia), excess hair (hypertrichosis, hirsutism), and abnormalities of the hair shaft. Occasionally, coloration of the hair may be an indication of systemic disease such as the dried, rusty brown hair of kwashiorkor or the white patch of Waardenberg syndrome. Important considerations in evaluating findings of alopecia and hypertrichosis include pattern and distribution and the condition of the underlying skin.

Common findings associated with nails also include those associated with systemic disease (eg, clubbing with chronic respiratory, cardiovascular, or hepatic disease) and problems specific to the nails. These

BOX 16-1 Common Skin Lesions

- Macules (flat, circumscribed lesions without palpable edges)
- Papules (raised lesions <1 cm)
- Cysts (sharply circumscribed)
- Movable lesions (below the epidermis)
- Nodules (elevated, circumscribed)
- Firm lesions (larger than papules)
- Tumors (large nodules)
- Vesicles (circumscribed, superficial collections of fluid in the epidermis <1 cm)
- Bullae (large vesicles, >1 cm)
- Scales (dried fragments of dead skin that often peel off spontaneously)
- Pustules (papules containing pus),
- Erosions (loss of superficial epidermis)
- Crusts (dried exudates)
- Lichenification (thick, dried plaques)
- Ulcers (deep erosions through the epidermis into the dermis)
- Indurations (hardening of the skin)
- Fissures (painful cracks)
- Scars

Table 16-12 Common Integumentary Findings

SITE	FINDING	NEWBORN AND INFANT	CHILD	ADOLESCENT
Skin	Red macules	Measles (maculopapular), roseola, Fifth disease, mononucleosis (less common in infants), ehrlichiosis, uritaria, drug eruption, urticaria pigmentosa, JIA, infection (cellulitis, erysipelas), first degree burns	Same as infant, but also consider measles, cytomegalovirus, Rocky Mountain spotted fever, mononucleosis (more common), JIA, SLE (malar rash), dermatomyositis, toxic shock, intertrigo, Kawasaki disease and expanding lesion of Lyme disease	Same as child
	Purple or blue macules	Blue nevus, purpura, petechiae, telangiectasia, trauma (ecchymosis)	Same as infant	Same as child
	Brown to black macules (hyper-pigmentation)	Nevi, lentigo syndromes, post-inflammatory (eczema, excoriations), fungal infection	Same as infant, but also consider café-au-lait spots (neurofibromatosis) Becker nevus, acanthosis nigrans	Same as child
	White macules (hypopigmenta-tion)	Piebaldism, incontinentia pigmentosa (postvascular lesions), vitiligo	Same as infant, but also consider tuberous pityriasis alba, tuberous sclerosis, halo nevus, tinea versicolor, postinflammatory hypopigmentation (eg, eczema, topical anti-inflammatory agents).	Same as child
	Red papules	Urticaria, insect bites, eczema, contact dermatitis, milia, Kawasaki disease, drug eruption	Same as infant (except milia), but also consider acne, granuloma anulare, folliculitis, scarlet fever, Lyme disease, warts, scabies, fungal infection, JIA	Same as child (except Kawasaki disease), acne becomes more common
	Cysts	Dermoid	Dermoid, epidermoid, steatocystoma, trichoepithelioma, vellus hair cyst, synovial (subdermal), cystic hygroma, lymphangioma	Same as child, cystic acne becomes more common.
	Noninflamed nodules	Neurofibroma	Dermatofibroma, angiofibroma, neurofibroma, neuroma, Cowden disease, rheumatoid arthritis, rheumatic fever	Same as child
	Inflamed nodules	Carbuncle, panniculitis	Same as infant, but also consider erythema nodosum, hydradenitis suppurativa	Same as child, but acne becomes more common
	Vesicles	Miliaria crystallina, dyshydrosis, contact dermatitis, hand-foot-mouth, varicella, primary HSV	Same as infant, but also consider recurrent HSV and herpes zoster	Same as child, but also consider HSV II
	Bullae	Burns, impetigo, scalded skin *(Staphylococcus),* epidermolysis bullosa	Same as infant, but also consider pemphigus vulgaris, bullous pemphigoid, Stevens-Johnson syndrome, toxic epidermal necrolysis	Same as child (except epidermolysis bullosa)
	Scales	Ichthyoses, hyperkeratosis, syndromes (Netherton, Sjögren-Larsson, KID, CHILD, Conradi)	Same as infant	Same as child, but also consider Refsum disease

Table 16-12 Common Integumentary Findings—cont'd

SITE	FINDING	NEWBORN AND INFANT	CHILD	ADOLESCENT
	Induration and sclerosis	Insect bites, infection	Infection, insect bites, sclerederma (post-*Streptococcus*), scleroderma	Same as child
	Atrophy	Scarring, progeria, Lawrence-Seip syndrome (rare), cutis aplasia	Same as infant, but also consider morphea, Ehlers-Danlos syndrome, striae, trauma, scarring	Same as child, but also consider necrobiosis lipoidica diabeticorum, Werner syndrome (rare)
	Ulcers	Neuropathic (toxic metal ingestion, spina bifida, diabetes), vasculitis, decubitus, trauma, infection	Same as infant, but also consider granulomas (inflammatory bowel disease, tuberculosis), cat scratch fever, balanitis *(Streptococcus)*, HSV, other infection (eg, Pseudomonas)	Same as child, but also consider gonorrhea, genital warts, self-mutilation
Hair	Hair loss (alopecia) with underlying skin abnormality	Nevus, hemangioma, hamartoma, incontinentia pigmenti and cutis aplasia (scarring), ectodermal dysplasia	Same as infant, but also consider chemical and thermal burns, tinea capitis, trichotillomania	Same as child
	Hair loss (alopecia) without underlying skin abnormality	Local rubbing (bed position), alopecia areata, local infection	Trauma, infection, alopecia areata (local), alopecia totalis and universalis (generalized), metabolic disorders (hyperthyroidism, homocystinuria), heavy metal intoxication	Same as child, but also consider self-mutilation (trichotillomania) and toxic reaction to use of chemical agents on hair
	Excess hair (hypertrichosis, hirsuitism)	Nevi, hamartoma (local), porphyria, drugs (eg, phenytoin), syndromes (mucopolysaccharidoses, leprechaunism, trisomy 18, Coffin-Siris, Marshall-Smith)	Same as infant, but also consider Cushing, adrenogenital, and polycystic ovary syndromes	Same as child
Nails	Underdeveloped (hypoplasia, aplastic)	In utero exposure to anticonvulsants, alcohol, and warfarin, congenital, Turner-Noonan syndrome, nail-patella syndrome, Lesch-Nyhan syndrome, chromosomal abnormalities	Same as infant	Same as child
	Pitting	Rare, usually a normal variant	Infection, psoriasis, normal variant after psoriasis	Same as child
	Abnormal shape (dystrophy)	Acrodermatitis enteropathica (zinc deficiency), ectodermal dysplasia, trauma	Same as infant, trauma self-inflicted or otherwise	Same as child
	Discoloration	Tetracycline exposure, subungual hematoma, trauma, Addison disease, jaundice, carotenemia, Wilson disease	Same as infant, but also consider chlorine phenothiazine exposure, endocarditis, melanoma, Peutz-Jeghers syndrome, uremia	Same as child, but also consider chronic tobacco use, fungal infection
	Spoon shape	Congenital (benign), Turner or Noonan syndrome, incontinentia pigmenti, iron deficiency	Same as infant, but also consider hemachromatosis	Same as child
	Brittle, dry	Malnutrition, ectodermal dysplasia, Plummer-Vinson syndrome, fungal infection, progeria, vitamin A deficiency (may be found in cystic fibrosis as presenting finding)	Same as infant, but also consider selenium poisoning, chronic disease, Reiter syndrome, thyroid disease, zinc deficiency	Same as child

CHILD, congenital hemidysplasia with icthyosiform erythroderma and limb defects; *HSV,* herpes simplex virus; *JIA,* juvenile idiopathic arthritis; *KID,* keratitis with icthyosis and deafness; *SLE,* systemic lupus erythematosus.

include absence, atrophy, dysplasia, hypertrophy of the nail bed, spoon shape, pitting, brittleness, separation, discoloration, ridging, and lines. Nail disorders are generally broadly classified as congenital or acquired.

Conditions associated with findings on the integument examination are found in Table 16-12.

ENDOCRINOLOGY

Endocrinologic and renal disease, by their very natures, stem from or produce systemic disease and findings. Many of these findings (eg, failure to thrive, short stature, hyperpigmentation, edema) could also occur from dysfunction in other organ systems. With a high index of suspicion derived from a thorough history and physical examination, and appropriate laboratory tests, a reasonable differential diagnosis and ultimately a diagnosis will be made. Because hormones can't be seen, and laboratory tests are not physical examination findings, this section and the section covering the renal system will discuss specific common physical findings that often must be further substantiated by testing. General observation, palpation, and measurement are the primary diagnostic tools used during a complete physical examination for endocrine problems.

Observation of the infant and child may lead to specific endocrine diagnoses such as lymphedema of the hands and feet, neck webbing, a shield-shaped chest, or the low hairline of Turner syndrome. If the infant has poor tone, suck, or feeding, or exhibits lethargy or fussiness, endocrine diagnoses that should be considered include hypoglycemia, hypocalcemia, and hypothyroidism. In an older child, fatigue and lethargy can be associated with hypothyroidism, hypoglycemia, and adrenal insufficiency. A rachitic rosary (prominent knobs along the sternal costochondral junctions) is associated with rickets. Infants who are small for their age may have intrauterine growth restriction (IUGR) from Turner syndrome or hypopituitarism, and large infants may have mothers with gestational diabetes or have Beckwith-Wiedemann syndrome. Underweight infants with normal length usually result from malnutrition, including underfeeding or malabsorption, as in cystic fibrosis. Adolescents with growth delay may have delay in attaining puberty because of constitution (familial growth pattern), but also because of hypogonadism or chronic disease (eg, severe cystic fibrosis). An open posterior fontanel after 1 to 2 months of age suggests hypothyroidism. Weight loss and dehydration can be presenting symptoms of type 1 diabetes mellitus at any age. Slow growth in an older child can occur with any chronic disease, but with the finding of poor growth velocity, growth hormone deficiency should be suspected. Agitation and tremors can arise from multiple causes, but hyperthyroidism should be included in the differential diagnosis. Hypocalcemia can cause muscles to be prone to irritation at any age.

Findings from the integument examination can suggest endocrine disorders. Acanthosis nigrans associated with insulin resistance is often found in obese adolescents. Obese children and adolescents may also have stretch striae on the abdomen, but when associated with cutaneous atrophy these suggest Cushing syndrome. The finding of hirsutism, particularly among females, suggests androgen excess, but can also be associated with hyperinsulinism. Dry or breaking hair and nonpitting edema suggest hypothyroidism. Bronzing of the skin (with no tan line) is associated with both Addison disease and congenital adrenal hyperplasia. Graves disease has associated exophthalmos and onycholytic (separation) nail changes. A mass in the neck may represent a goiter and, if painful, thyroiditis. Undescended testes may be because of prematurity or chromosomal and nonchromosomal syndromes usually associated with primary dysgenetic hypogonadism in males, but may also represent female virilization in congenital adrenal hyperplasia.

Microphallus suggests hypopituitarism, androgen insensitivity, or premature testicular failure. Early breast development can indicate exogenous exposure to estrogen or precocious puberty, especially if associated with premature development of pubic hair and accelerated growth.

Common findings associated with endocrine disorders are presented in Table 16-13.

RENAL

As with the endocrine system, suspected renal diagnosis is typically made through laboratory evaluation. In addition, renal disease is often a secondary problem related to other systemic disease or drugs. Measurement, observation, and palpation are the most commonly utilized aspects of the physical examination when evaluating children for renal disease. Common findings include hypertension, edema, bruising, heart murmur, fever, purpura, flank mass, flank tenderness, and abdominal tenderness. As with other chronic disease, children with chronic renal disease may present with growth failure, and a workup for this condition should include a renal evaluation.

Hypertension in the newborn and infant may be a finding in renal diseases including renal vein thrombosis, renal tumor, adrenal tumor, and polycystic kidneys. In the older child or adolescent, it can be an intermittent manifestation of acute or chronic glomerulonephritis or may be secondarily associated with volume overload from hypoproteinemia. Edema as a finding in renal disease is associated with nephrotic syndrome, glomerulonephritis, membranous nephropathy, and focal sclerosis. Bruising can occur with coagulopathies and collagen-vascular disease; frank purpura with systemic infection and Henoch-Schönlein purpura. A flank mass may represent a polycystic kidney, urinary obstruction, tumor, or multicystic dysplasia. Flank tenderness is most often caused by pyelonephritis but may also represent trauma or urolithiasis. Abdominal tenderness can be a manifestation of renal colic because of urolithiasis, tumors, infection, or other urinary obstruction.

More common conditions associated with the renal findings in this section are summarized in Table 16-14.

HEMATOLOGY/ONCOLOGY

Like findings associated with endocrine and renal disorders, hematologic and oncologic problems usually present with manifestations in other systems and a

Table 16-13 Common Endocrine Findings

SITE	FINDING	NEWBORN AND INFANT	CHILD	ADOLESCENT
General	Short stature	IUGR, Turner syndrome, Russell-Silver syndrome, social deprivation, hypothyroidism	Constitution (familial growth pattern), Turner syndrome, growth hormone deficiency, Cushing syndrome, Prader-Willi syndrome, chronic inflammatory diseases, chronic oral steroid therapy, hypothyroidism	Same as child, but consider delayed puberty
	Tall stature	Beckwith-Wiedemann syndrome	Growth hormone–producing tumors, acromegaly, obesity, precocious puberty	Same as child, but also consider Klinefelter and Marfan syndromes
	Underweight (failure to thrive or gain weight)	Hyperthyroidism, diabetes mellitus, social deprivation	Same as infant	Same as child, but also consider anorexia and bulemia
	Overweight	Hyperinsulinism, overnutrition	Prader-Willi syndrome, Cushing syndrome, metabolic syndrome, overeating, reduced physical activity	Same as child
	Hyperreflexia	Hyperthyroidism	Same as infant	Same as infant
	Chvostek, Trousseau signs	Hypocalcemia	Same as infant	Same as infant
	Hyporeflexia	Hypothyroidism	Same as infant	Same as infant
Head	Open posterior fontanel	Hypothyroidism	NA	NA
Neck	Thyroid gland enlargement (painless goiter)	Iodine deficiency, enzymatic defects	Same as infant, but also consider Graves disease, Hashimoto thyroiditis, subacute hypothyroidism, malignancy	Same as child
	Painful goiter	NA	Subacute thyroiditis	Same as child
	Cystic mass in the midline anteriorly	Thyroglossal duct cyst, ectopic thyroid gland	Same as infant	Same as child
	Webbing with low hair line	Turner syndrome, Noonan syndrome	Same as infant	Same as infant
Chest wall	Pectus excavatum and rachitic rosary (see text)	Rickets	Same as infant	Same as infant
Skin	Dry, thickened, waxy	Hypothyroidism	Same as infant	Same as infant
	Thin with purple striae	Cushing syndrome	Same as infant	Same as infant
	Café-au-lait spots	NA	McCune-Albright syndrome, neurofibromatosis	Same as child
	Generalized bronzing (with-out tan line)	Addison disease	Same as infant	Same as infant
Nails	Spoon-like	Noonan syndrome	Same as infant	Same as infant
	Onycholysis	Rare	Graves disease, fungal infection, psoriasis	Same as child
Cardiovascular	Hypotension	Addison disease, salt wasting congenital adrenal hyperplasia, diabetes insipidus	Same as infant	Same as infant

Continued

Table 16-13 Common Endocrine Findings—cont'd

SITE	FINDING	NEWBORN AND INFANT	CHILD	ADOLESCENT
	Hypertension	Rarely caused by endocrine problems	Cushing syndrome, metabolic syndrome, pheochromocytoma, Turner syndrome, Graves disease, chronic oral steroid therapy	Same as child
	Widened pulse pressure	Graves disease	Same as infant	Same as infant
	Murmur	Graves disease, Turner syndrome with coarctation of the aorta	Same as infant	Same as infant
Breast	Early development	May be physiologically normal in early infancy	Precocious puberty, benign follicular cyst, exposure to estrogens	NA
	Painful breast bud	Rare	Normal in early puberty	NA
	Galactorrhea	May be physiologically normal in early infancy	Drugs, prolactinoma, local infection	Same as child, but also consider pregnancy
	Breast development in males (gynecomastia)	May be physiologically normal in early infancy	Estrogen-producing tumor, drugs	Physiologic, Klinefelter syndrome, anorchia, defects in testosterone metabolism, feminizing adrenal tumors, drugs, exogenous estrogens
Male genitalia	Undescended testes	Prematurity, hereditary, genetic syndromes, androgen insensitivity	Same as infant except prematurity	Same as child
	Asymmetric testicular enlargement	Testicular tumors, hydrocele	Same as infant	Same as infant
	Painful testicular enlargement	Testicular torsion	Same as infant	Same as infant
	Micropenis	Hypopituitarism, androgen insensitivity	Same as infant	Same as infant
	Hypospadias	Disorder of sexual differentiation, Opitz syndrome, androgen receptor abnormalities	Same as infant	Same as infant
Pubic hair	Premature appearance	Idiopathic premature adrenarche, virilizing congenital adrenal hyperplasia, androgen-producing tumors	Same as infant	NA

IUGR, intrauterine growth restriction.

high index of suspicion as a result of a thorough history. Physical examination and judicious laboratory evaluation are necessary to make a diagnosis. The only specific system involved is the hematopoietic system, and oncologic disease can occur in any system, including the bone marrow. Table 16-15 lists general findings that could relate to hematology/oncology problems, but in most cases these findings cross organ systems with other etiologies. These general findings include jaundice, pallor, mucus membrane bleeding, epistaxis, gastrointestinal bleeding, other spontaneous bleeding, petechiae, purpura, bruising, tissue and bone swelling, joint pain, and lymphadenopathy because of disturbance in the hematopoietic system. Oncologic findings, other than those related to the hematopoietic system, most often present with

Table 16-14 Common Renal Findings

SITE	FINDING	NEWBORN AND INFANT	CHILD	ADOLESCENT
General	Hypertension	Renal vein thrombosis, renal artery stenosis, tumor (renal, adrenal), polycystic kidneys, fluid (volume) overload	Fluid overload, acute renal failure, chronic renal failure, tumor, renal vein thrombosis, acute glomerulonephritis, vasculitic disorders, chronic oral steroid therapy	Same as child
Skin	Edema	Fluid overload, nephrotic syndrome, proteinuria secondary to glomerulonephritis, membranous nephropathy, focal sclerosis, protein malnutrition	Same as infant, but also consider nephrotoxins and nephrotoxic drugs, SLE	Same as child
	Bruising	Coagulopathy, renal vein or artery thrombosis, tumor, drugs, vasculitis secondary to vasculitic disorders, HSP, hemolytic uremic syndrome	Same as infant	Same as infant
	Purpura	HSP, infection with shock and acute renal failure, hematologic and oncologic problems	Same as infant, also HSP	Same as child
Flank	Mass	Polycystic kidney, urinary obstruction, tumor, multicystic dysplasia, trauma, acute pyelonephritis, Beckwith-Wiedemann syndrome	Same as infant	Same as infant
	Tenderness	Rare finding (examination is difficult)	Acute pyelonephritis, urolithiasis, trauma, tumor	Same as child, but also consider sexually transmitted infection
Abdomen	Tenderness	Rare finding (examination is difficult)	Obstructive uropathy, urolithiasis, urinary tract infection, tumor, trauma	Same as child

HSP, Henoch-Schönlein purpura; *SLE,* systemic lupus erythematosus.

Table 16-15 Common Hematologic Findings

SITE	FINDING	NEWBORN AND INFANT	CHILD	ADOLESCENT
Skin	Petechiae, ecchymoses, purpura	Inherited disorders of coagulation, acquired disorders of coagulation because of infection, toxins, trauma, autoimmune disease, HSP, platelet dysfunction, thrombocytopenia from any cause, rheumatic and vasculitic disorders	Same as infant, but also consider acquired immunodeficiency	Same as child
	Pallor	Anemia (iron deficiency, hemolytic, occult blood loss), blood loss from any site, suppressed bone marrow from drugs or toxins, inherited anemias (sickle cell disease, Diamond-Blackfan syndrome, TEC, anemia of chronic disease, malabsorption syndromes, hemolytic-uremic syndrome	Same as infant, but TEC rare	Same as child (except TEC)
	Jaundice	Hemolytic anemias, liver or biliary tumor	Same as infant	Same as infant
	Enlarged lymph nodes	Infection, tumor (lymphoma, leukemia), rheumatic and vasculitic disorders	Same as infant	Same as infant
Abdomen	Enlarged liver and spleen (hepatosplenomegaly)	Infection, tumor, hemolytic anemias (sickle cell disease), spherocytosis, rheumatic and vascultic disorders	Same as infant	Same as infant

HSP, Henoch-Schönlein purpura; *TEC,* transient erythroblastpenia of childhood.

masses that may obstruct organs and cause secondary symptoms. Discovery of an abdominal mass should prompt the physician to consider lymphoma, Wilms tumor, neuroblastoma, hepatoblastoma, teratoma, and germ cell tumors.

Spontaneous bleeding and easy bruising are always cause for concern in a infant, child, or adolescent, and are most often caused by coagulation and clotting disorders, platelet disorders, vitamin K deficiency, infection, malignancy, or vasculitic disorders. Pallor with normal cardiovascular status usually indicates anemia, which could have many causes, including bone marrow malignancies. Jaundice from hematologic causes results from rapid breakdown of red blood cells. Petechiae and bruising (ecchymoses) should always lead the physician to consider trauma (accidental or nonaccidental) but again are a manifestation of platelet deficiency or dysfunction. Purpura may be caused by autoimmune disease or infection, but could also be a consequence of extensive intradermal bleeding from other causes. Swelling, especially in a joint, should cause the physician to consider hemarthrosis.

SUMMARY

The physician who thinks broadly and logically about a specific finding after performing a complete history, review of systems, and a physical examination is ahead of the game in forming a sound differential diagnosis and, ultimately, coming to a diagnostic conclusion. Findings usually span multiple organ systems and usually are consistent from one examination period to another (but not always if exacerbations and remissions occur spontaneously). Age-appropriate differential diagnoses must always be considered. Like symptoms, findings are, in the words of Jean-Martin Charcot (1825–1893), "in reality nothing but the cry from suffering organs."

TOOLS FOR PRACTICE

Medical Decision Support

- *Age-based Pediatric Blood Pressure Reference Charts* (calculator), Baylor College of Medicine (www.bcm.edu/bodycomplab/Flashapps/BPVAgeChartpage.html)

AAP POLICY

American Academy of Pediatrics Section on Ophthalmology and Committee on Practice and Ambulatory Medicine, American Academy of Ophthalmology, American Association for Pediatric Ophthalmology and Strabismus, American Association of Certified Orthoptists. Instrument-based pediatric vision screening policy statement. *Pediatrics*. 2012;130(5):983–986 (pediatrics.aappublications.org/content/130/5/983)

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Chapter 17

SPORTS PREPARTICIPATION PHYSICAL EVALUATION

David T. Bernhardt, MD

More than 7 million high school students participate in sports each year, making the preparticipation physical evaluation (PPE) one of the most commonly performed examinations. Over the last decade, the PPE has evolved to allow physicians to provide consistent, high-quality examinations nationwide. In the early 1990s, the American Academy of Family Physicians, the American Academy of Pediatrics (AAP), the American Medical Society for Sports Medicine, the American Orthopaedic Society for Sports Medicine, and the American Osteopathic Academy of Sports Medicine formed the Preparticipation Examination Task Force to standardize the conduct and content of these examinations. In 1992, the Task Force published recommendations for the PPE based on the consensus of the current literature. These guidelines were updated in 1997, 2002, 2004, and 2010 and serve as the basis for the current PPE.

GOALS OF THE PREPARTICIPATION PHYSICAL EVALUATION

The purpose of the PPE is to promote the health and safety of the young athlete in training and competition. Because pediatricians should counsel all patients to be physically active, the definition of athlete should include all pediatric patients.

The primary goals of the PPE are to detect conditions that might be life threatening, predispose the athlete to injury, or be disabling; and to meet legal or insurance requirements. The secondary goals are to determine general health, counsel athletes on health-related issues, update medications and immunizations, and establish a medical home. The secondary goals are part of the health supervision visit performed in the office as a routine part of the child or adolescent's health care.

Parents sometimes expect the PPE to be a comprehensive evaluation of the athlete's health, including areas that may be considered unrelated to sports participation, such as sexuality, substance abuse, and immunizations. Parents often use the PPE as the only medical evaluation for their child or adolescent. In contrast, many physicians view the PPE as a cursory examination that is only intended to detect conditions that might limit or impair athletic endeavors. Answers

BOX 17-1 Common Questions Parents Have About the Preparticipation Physical Evaluation (PPE)

My son had a physical examination for participation in football last year. Does he still need to see his physician this year?

Although the PPE is comprehensive, it was never designed to take the place of a regular physician visit. The setting or time allocation for the PPE is often not conducive to discussions of health issues that are of primary importance during the adolescent years, such as drug and alcohol use, smoking, sexual activity education, safety issues, and diagnosis of depression. Therefore, the PPE should really be a small portion of a standard health supervision visit for all active patients.

When should my child have a PPE relative to the beginning of an athletic season?

The best time for the PPE is approximately 4 to 6 weeks before the beginning of the athletic season. This period allows enough time for thorough evaluations, consultations, and rehabilitation of any identified musculoskeletal injuries.

Do I need to attend the PPE with my child?

Although you may not be asked to attend the PPE with your child, you should review the accuracy and completeness of the medical history and family history provided. Your child may not know or remember some of the history. Most of the important information obtained in the PPE is obtained from the history.

How often will my son or daughter need a PPE?

The frequency of required evaluations varies by state. Most commonly, a PPE is required every other year. To determine the requirements of your state, check with the school district or the state high school athletic association.

Will my child need to undergo any laboratory or radiographic studies at the PPE?

Routine laboratory studies and radiographs are not generally performed. Based on information obtained during the history and physical examination, however, your physician may think that further studies are indicated.

to common questions parents have about the PPE are provided in Box 17-1.

Because parents and physicians view the evaluation differently, parents must be advised about the intent of the PPE, and the PPE's scope and purpose must be made clear to them. The most recent PPE guidelines suggest creating a medical home for all athletes (see Chapter 6, Medical Home Collaborative Care).

CONDUCTING THE PREPARTICIPATION PHYSICAL EVALUATION

Methods

The PPE is typically conducted using either the station-based method or the office-based method.

The station-based method divides the examination into several components, with physicians, nurses, athletic trainers, and coaches each assigned to a single task. This method is ideally suited for screening large numbers of athletes. Two benefits of this method are that it is relatively efficient and provides timely access to complete the PPE. However, this method affords less rapport with athletes, and privacy may be lacking. In addition, lack of access to parents and medical records may hinder the accuracy of the history. Without medical records being available, athletes and parents may hide crucial medical information in an attempt to get the athlete cleared for participation. Athletes have little opportunity to ask questions of the physicians regarding their own health or other medical or personal issues. Stations usually utilized in this situation include, but are not limited to, vital signs, vision screening, medical history and examination, orthopedic history and examination, an immunization station, and a checkout station.

The individual office-based method has the advantage of the screening examination being performed in the medical home or office with an established physician–patient relationship in which the medical history is known and continuity of care is fostered. Disadvantages may include a lack of consistency among physicians and their potential unfamiliarity with the sport and its disqualifying conditions.

Timing

Ideally, the PPE is performed early enough before the sport's season begins to ensure that athletes who have medical problems can be thoroughly evaluated and treated, but not so early that intervening injuries are likely to occur. The best time for the evaluation to take place is 6 weeks prior to the first scheduled practice.

Although the current AAP guidelines suggest that the PPE should be performed every year, other sources suggest that the PPE be conducted before the beginning of each new level of competition (ie, middle school or junior high, high school, college), with annual updates of the history and targeted physical examinations of areas of concern. However, most state high school athletic associations require evaluations every other year.

EVALUATION

History

As in any health evaluation, the history identifies most potential problems for young athletes. Most experts agree that, despite the best screening of athletes to prevent sudden death, it is a rare occurence to actually detect a condition that would possibly place the athlete at risk for sudden cardiac death. The key to identifying these problems is a questionnaire that systematically screens for conditions that often cause problems in athletes or that might lead to sudden death during athletic activity. Table 17-1 lists some of the most important questions to ask during the examination. PPE forms provided by state high school athletic associations may not incorporate all of the screening questions recommended by the Preparticipation

Table 17-1 Medical History Questions

QUESTION	REASON
1. Injury or illness since last checkup?	Targets potential physical examination concerns
2. Chronic illnesses, hospitalizations, or surgeries?	Identifies potential counseling or rehabilitation issues
3. Any medications or supplements of any type?	Identifies drugs that may inhibit or interfere with sports participation
4. Allergies to medications, insects, or food?	Alerts physicians and trainers for potential allergic reactions
5. Dizziness, passing out, chest pain with exercise? History of sudden death in a close relative?	Identifies potential causes of sudden death caused by cardiovascular problems
6. Have you ever passed out or nearly passed out during exercise? Have you ever passed out or nearly passed out after exercise? Have you ever had discomfort, pain, or pressure in your chest during exercise? Does your heart race or skip beats during exercise? Does anyone in your family have Marfan syndrome?	Targets cardiovascular concerns
7. Ever been restricted from sports by physician?	Identifies potential disqualifying problems
8. Any skin problems?	Identifies potential transmittable disease during contact
9. Concussion, knocked out, unconsciousness, memory loss, seizure, or severe or frequent headache?	Targets neurologic concerns
10. Stinger, burner, pinched nerve, numbness or tingling in extremities?	Targets neurologic concerns
11. Problems while exercising in the heat?	Targets heat illness concerns
12. Asthma, allergies, wheezing, difficulty breathing, or chest pain?	Identifies potential for exercise-induced asthma
13. Special equipment or devices not usually used in your sport?	Identifies potential concerns for physician follow-up
14. Glasses, contacts, or vision or eye problems?	Identifies ophthalmologic concerns
15. Strain, sprain, fracture, joint pain, or swelling?	Identifies potential musculoskeletal problems
16. Concerns about weight: Do you lose weight regularly for your sport?	Identifies potential disordered eating
17. Feel stressed out?	Clue to ask follow-up questions regarding drug use, eating problems, sexuality, and home and school problems
18. Recent immunizations (tetanus, measles, hepatitis B, chicken pox)?	Health maintenance issues
19. Girls only: menstrual history?	Identifies oligomenorrhea and amenorrhea and potential risk for poor nutrition, stress fractures
20. Do you wear protective braces, splints?	Identifies injuries that have not been fully rehabilitated

Examination Task Force. The AAP provides a recommended standardized form (see Tools for Practice at the end of this chapter.)

One study showed that only 40% of PPE forms matched when filled out independently by parent and child. The athlete and the parents should, therefore, complete the form together to obtain a thorough and accurate history. Although the PPE forms should be completed by parent and patient, some issues may arise (particularly for those patients for whom the practice is the medical home) in which adolescent privacy on certain topics, such as sexuality and substance abuse, should be respected. A confidential form, such as the Guidelines for Adolescent Preventive Services (GAPS) form, should be completed by the adolescent when addressing these issues.

Physical Examination

Two key components of the physical examination—cardiovascular and musculoskeletal—identify most athletes who warrant further evaluation or disqualification. The updated medical evaluation form recommended by the Preparticipation Examination Task Force can be accessed on the AAP Web site (see Tools for Practice at the end of this chapter).

Cardiovascular Examination

The cardiovascular examination should include evaluation of peripheral pulses, murmurs, and blood pressure. Table 17-2 summarizes important aspects of the cardiovascular examination screening. All diastolic murmurs and grade 3/6 systolic murmurs warrant further evaluation. Hypertrophic cardiomyopathy, one

Table 17-2 Cardiovascular Screening in Athletes

CONDITION	CARDIOVASCULAR EXAMINATION	ABNORMALITY
Hypertension	Blood pressure	Varies with age; general guideline is >135/85 mm Hg in adolescents
Coarctation of aorta	Femoral pulses	Decreased intensity of pulse
Hypertrophic cardiomyopathy	Auscultation with provocative maneuvers (standing, supine, Valsalva maneuver)	Systolic ejection murmur that intensifies with standing or Valsalva maneuver
Marfan syndrome	Auscultation	Aortic (decrescendo diastolic murmur) or mitral insufficiency (holosystolic murmur)

Derived from Maron BJ, Thompson PO, Puffer JC. Cardiovascular preparticipation screening of competitive athletes: a statement from the Sudden Death Committee [clinical cardiology] and Congenital Cardiac Defects Committee [cardiovascular disease in the young] American Heart Association. *Circulation.* 1996;94:850–856.

of the most important conditions to detect, may produce a systolic murmur that cannot be distinguished from an innocent murmur. The murmur of hypertrophic cardiomyopathy increases in intensity with a Valsalva maneuver (decreased ventricular filling, increased obstruction) and decreases with squatting (increased ventricular filling, decreased obstruction); it will also increase in intensity when the athlete moves from a squatting to standing position.

Blood pressures obtained during the PPE are often high. These readings are sometimes the result of using a blood pressure cuff that is too small, particularly in large adolescents. However, sometimes the athlete's blood pressure is truly high when an age-based table of norms is consulted. Hypertension is rarely severe enough to disqualify an athlete from participation, but it needs to be identified and monitored by the athlete's regular physician. Weight-training activities should be restricted in patients who have severe hypertension. Diagnostic tests, such as electrocardiograms, are still not universally accepted as a standard of care at this time. A low positive predictive value, a lack of trained or expert clinicians adept at interpreting electrocardiograms in athletes, and cost are most often cited as the reasons for this. Continued investigation into the cost-effectiveness and standardization of electrocardiogram interpretation in athletes may change this recommendation in the future.

Although sudden cardiac death in young athletes is rare, a positive response to the cardiac history questions detailed in the PPE monograph and history form warrants further, more detailed evaluation.

Musculoskeletal Examination

The musculoskeletal examination is particularly important because it typically accounts for 50% of the abnormal physical findings identified on the PPE. The examination should focus on previously injured or symptomatic areas. Ninety-two percent of orthopedic injuries are detected by history alone.

Some authorities suggest a sport-specific approach to the physical examination. This method emphasizes the areas that are most commonly affected or injured in each specific sport. For example, a swimmer's examination would focus on the shoulders, whereas a football player's examination would include evaluation of neurologic conditions and musculoskeletal injuries.

BOX 17-2 Special Considerations for the Examination of Injured or Symptomatic Joints

- Inspect for visual deformity, muscle mass, asymmetry, and swelling.
- Palpate for localized areas of tenderness, warmth, and effusion.
- Assess range of motion (eg, an athlete with hip pain should be tested for loss of internal rotation and abduction, which can be seen in slipped capital femoral epiphysis and Legg-Calvé-Perthes disease).
- Test neurovascular status by evaluating muscle strength, sensation, reflexes, and pulses of the involved limb (eg, an athlete with a history of burners should undergo complete neurovascular testing of the neck and upper extremities).
- Test joint stability (eg, an athlete with knee pain should undergo tests for valgus and varus stress, Lachman test, and posterior drawer test).

Box 17-2 lists special considerations for the examination of injured or symptomatic joints.

Laboratory Studies

Laboratory studies have not been shown to be cost-effective or warranted in young, asymptomatic athletes. Routine urinalysis and hematocrit for all athletes have been largely abandoned because these tests do not identify athletes who require disqualification, and they have a high rate of false-positive results. Similarly, electrocardiography, echocardiography, and stress testing are not suggested as screening tests in asymptomatic individuals because of the high rate of false-positive findings and high cost.

SPORTS CLASSIFICATION

Sports are classified based on the likelihood of collision injury and the strenuousness of the exercise. These classifications are used to guide physicians on the risk

BOX 17-3 Sport Classification by Contact

CONTACT OR COLLISION

- Basketball
- Boxing
- Crew rowing
- Diving
- Field hockey
- Football (flag, tackle)
- Ice hockey
- Lacrosse
- Martial arts
- Rodeo
- Rugby
- Ski jumping
- Soccer
- Team handball
- Water polo
- Wrestling

LIMITED CONTACT

- Baseball
- Bicycling
- Cheerleading
- Canoeing and kayaking (white water)
- Fencing
- Field events (high jump, pole vault)
- Floor hockey
- Gymnastics
- Handball
- Horseback riding
- Racquetball
- Skating (ice, in-line, roller)
- Skiing (downhill, water)
- Softball
- Squash
- Ultimate frisbee
- Volleyball
- Windsurfing and surfing

NONCONTACT

- Archery
- Badminton
- Bodybuilding
- Canoeing and kayaking (flat water)
- Crew rowing
- Curling
- Dancing
- Field events (discus, javelin, shot put)
- Golf
- Orienteering
- Power lifting
- Race walking
- Riflery
- Rope jumping
- Running
- Sailing
- Scuba diving
- Strength training
- Swimming
- Table tennis
- Tennis
- Track
- Weight lifting

Adapted from American Academy of Pediatrics Committee on Sports Medicine and Fitness. Medical conditions affecting sports participation. *Pediatrics*. 2008; 121(4):841–848.

of injury and the degree of cardiopulmonary fitness required to engage in the sport successfully. The AAP has established classification guidelines by the level of contact and intensity (see Box 17-3 and Table 17-3).

CLEARANCE TO PLAY

Few athletes are disqualified from activity based on conditions identified during the PPE. Table 17-4, which is designed to be understood by both medical and nonmedical personnel, lists the most current recommendations regarding medical conditions and contraindications to participation. Working with athletes to find safe, enjoyable sports in which they can participate is important. If possible, and depending on the condition that is detected, sports participation should not be eliminated altogether. Figure 17-1 provides a sample of a form used for clearance for return to play.

Occasionally, an athlete or parent will disagree with a physician's recommendation for restricting participation in a particular sport. In these cases, the important steps are to explain fully the reasons for the recommendation and to consider having the athlete and parent sign a document acknowledging that this discussion occurred and that they were informed of the risks. Athletes may request a second opinion, and this is often reasonable when making important decisions related to clearance. Ultimately, the team physician is responsible for ensuring that athletes are able to participate safely and without undue risk of injury.

SPECIAL CONSIDERATIONS

Nutritional Supplements

Sports supplements have become a billion-dollar industry. Athletes as young as age 11 years are taking

Table 17-3 Sports Classification by Intensity

HIGH-TO-MODERATE INTENSITY; HIGH-TO-MODERATE DYNAMIC; HIGH-TO-MODERATE STATIC DEMANDS	HIGH-TO-MODERATE INTENSITY; HIGH-TO-MODERATE DYNAMIC; LOW STATIC DEMANDS	HIGH-TO-MODERATE INTENSITY; HIGH-TO-MODERATE STATIC; LOW DYNAMIC DEMANDS	LOW INTENSITY; LOW DYNAMIC; LOW STATIC DEMANDS
• Boxing	• Badminton	• Archery	• Bowling
• Cross-country skiing	• Baseball	• Auto racing	• Cricket
• Cycling	• Basketball	• Diving	• Curling
• Downhill skiing	• Field hockey	• Equestrian	• Golf
• Fencing	• Lacrosse	• Field events (jumping, throwing)	• Rifle shooting
• Football	• Orienteering	• Gymnastics	
• Ice hockey	• Table tennis	• Karate or judo	
• Rugby	• Race walking	• Motorcycling	
• Running (sprint)	• Racquetball	• Rodeo	
• Speed skating	• Soccer	• Sailing	
• Water polo	• Squash	• Ski jumping	
• Wrestling	• Swimming	• Waterskiing	
	• Tennis	• Weight lifting	
	• Volleyball		

Adapted with permission from Mitchell JR, Haskell W, Snell P, Van Camp SP. Task Force 8: classification of sports. *J Am Coll Cardiol.* 2005;45(8):1364–1367.

Table 17-4 Medical Conditions and Sports Participation

CONDITION	PARTICIPATE?	EXPLANATION
Atlantoaxial instability (instability of the joint between cervical vertebrae 1 and 2)	Qualified yes	Athlete needs evaluation[a] to assess risk of spinal cord injury during sports participation.
Bleeding disorder	Qualified yes	Athlete needs evaluation.
Carditis (inflammation of the heart)	No	Carditis may result in sudden death with exertion.
Hypertension (high blood pressure)	Qualified yes	Persons with significant essential (unexplained) hypertension should avoid weight lifting and power lifting, bodybuilding, and strength training. Those with secondary hypertension (hypertension caused by a previously identified disease) or severe essential hypertension need evaluation.
Congenital heart disease (structural heart defects present at birth)	Qualified yes	Persons with mild forms may participate fully; those with moderate or severe forms or who have undergone surgery need evaluation.
Dysrhythmia (irregular heart rhythm)	Qualified yes	Athlete needs evaluation because some types require therapy or make certain sports dangerous, or both.
Mitral valve prolapse (abnormal heart valve)	Qualified yes	Persons with symptoms (chest pain, symptoms of possible dysrhythmia) or evidence of mitral regurgitation (leaking) on physical examination need evaluation. All others may participate fully.
Heart murmur	Qualified yes	If the murmur is innocent (does not indicate heart disease), then full participation is permitted; otherwise the athlete needs evaluation (see "Congenital heart disease" and "Mitral valve prolapse" above).
Cerebral palsy	Qualified yes	Athlete needs evaluation.
Diabetes mellitus	Yes	All sports can be played with proper attention to diet, hydration, and insulin therapy. Particular attention is needed for activities that last 30 minutes or more.
Diarrhea	Qualified no	Unless disease is mild, no participation is permitted, because diarrhea may increase the risk of dehydration and heat illness. See "Fever" below.

Continued

Table 17-4 Medical Conditions and Sports Participation—cont'd

CONDITION	PARTICIPATE?	EXPLANATION
Eating disorders, anorexia nervosa, bulimia nervosa	Qualified yes	These patients need both medical and psychiatric assessment before participation.
Eyes: functionally one-eyed athlete, loss of an eye, detached retina, previous eye surgery or serious eye injury	Qualified yes	A functionally one-eyed athlete has a best-corrected visual acuity of <20/40 in the worse eye. These athletes would experience significant disability if the better eye were seriously injured, as would those with loss of an eye. Some athletes who have previously undergone eye surgery or had a serious eye injury may have an increased risk of injury because of weakened eye tissue. Availability of eye guards approved by the American Society for Testing Materials and other protective equipment may allow participation in most sports, but this determination must be made on an individual basis.
Fever	No	Fever can increase cardiopulmonary effort, reduce maximal exercise capacity, make heat illness more likely, and increase orthostatic hypotension during exercise. Fever may rarely accompany myocarditis or other infections that may make exercise dangerous.
History of heat illness	Qualified yes	Because of the increased likelihood of recurrence, the athlete needs individual assessment to determine the presence of predisposing conditions and to arrange a prevention strategy.
Human immunodeficiency virus infection	Yes	Because of the apparent minimal risk to others, all sports may be played that the state of health allows. In all athletes, skin lesions should be properly covered, and athletic personnel should use universal precautions when handling blood or body fluids with visible blood.
Kidney: absence of one	Qualified yes	Athlete needs individual assessment for contact or collision and limited contact sports.
Liver: enlarged	Qualified yes	If the liver is acutely enlarged, then participation should be avoided because of risk of rupture. If the liver is chronically enlarged, then individual assessment is needed before collision or contact or limited contact sports are played.
Malignancy	Qualified yes	Athlete needs individual assessment.
Musculoskeletal disorders	Qualified yes	Athlete needs individual assessment.
History of serious head or spine trauma, severe or repeated, concussions, or craniotomy	Qualified yes	Athlete needs individual assessment for collision or contact or limited contact sports and for noncontact sports if deficits exist in judgment or cognition. Recent research supports a conservative approach to management of concussions.
Convulsive disorder (well controlled)	Yes	Risk of convulsion during participation is minimal.
Convulsive disorder (poorly controlled)	Qualified yes	Athlete needs individual assessment for collision or contact or limited-contact sports. Avoid the following noncontact sports: archery, rifle shooting, swimming, weight lifting or power lifting, strength training, or sports involving heights. In these sports, occurrence of a convulsion may be a risk to self or others.
Obesity	Qualified yes	Because of the risk of heat illness, obese persons need careful acclimatization and hydration.
Organ transplant recipient	Qualified yes	Athlete needs individual assessment.
Ovary: absence	Yes	Risk of severe injury to the remaining ovary is minimal.
Respiratory, pulmonary compromise (including cystic fibrosis)	Qualified yes	Athlete needs individual assessment but generally all sports may be played if oxygenation remains satisfactory during a graded exercise test. Patients with cystic fibrosis need acclimatization and good hydration to reduce the risk of heat illness.
Asthma	Yes	With proper medication and education, only athletes with the most severe asthma will have to modify their participation.

Table 17-4 Medical Conditions and Sports Participation—cont'd

CONDITION	PARTICIPATE?	EXPLANATION
Acute upper respiratory infection	Qualified yes	Upper respiratory obstruction may affect pulmonary function. Athlete needs individual assessment for all but mild diseases. See "Fever."
Sickle cell disease	Qualified yes	Athlete needs individual assessment. In general, if status of the illness permits, then all but high-exertion, collision, or contact sports may be played. Overheating, dehydration, and chilling must be prevented.
Sickle cell trait	Yes	Individuals with sickle cell trait do not likely have an increased risk of sudden death or other medical problems during athletic participation except under the most extreme conditions of heat and humidity and possibly high altitude. These individuals, as with all athletes, should be carefully conditioned, acclimatized, and hydrated to reduce any possible risk.
Skin: boils, herpes simplex, impetigo, scabies, molluscum contagiosum	Qualified yes	Because the patient is contagious, participation in gymnastics with mats, martial arts, wrestling, or other collision or contact or limited-contact sports is not allowed. Herpes simplex virus is probably not transmitted via mats.
Spleen: enlarged	Qualified yes	Persons with acutely enlarged spleens should avoid all sports because of risk of rupture. Those with chronically enlarged spleens need individual assessment before playing collision or contact or limited contact sports.
Testicle: absent or undescended	Yes	Certain sports may require a protective cup.

[a]*Needs evaluation* means that a physician with appropriate knowledge and experience should assess the safety of a given sport for an athlete with the listed medical condition. Unless otherwise noted, this term is used because of the variability of the severity of the disease, the risk of injury among the specific sport, or both.
Adapted from American Academy of Pediatrics Committee on Sports Medicine and Fitness. Medical conditions affecting sports participation. *Pediatrics.* 2008;121(4):841–848.

performance-enhancing supplements. Sports supplements contain impurities, and when taken inappropriately, they may result in adverse side effects, which can include muscle cramps, dehydration, abdominal bloating, tachycardia, arrhythmia, and even death. Supplement use should be discouraged in most scenarios. The PPE is an ideal time to question athletes briefly about supplement use.

Obesity

Childhood obesity has reached epidemic proportions. Up to 30% of children are obese, and many of these youngsters are seeking to participate in sports. Obesity is not a contraindication to sports participation unless a comorbid finding such as severe hypertension is found. Obese children are at increased risk of heat injury and should be counseled accordingly. Sports participation with emphasis on activities that improve fitness should be encouraged for the obese child.

Concussion

A history of previous concussions should be addressed during the PPE. Consensus related to concussion management continues to evolve with more evidence to help guide management. Concussions that require a long time for recovery, or that involve significant amnesia, prolonged loss of consciousness, or seizure, should be thoroughly evaluated by either a sports medicine professional or neurologist. Neuropsychologic testing is suggested with repeat concussions or complicated concussion. Patients must meet 3 criteria to return to play: they must be asymptomatic at rest, be asymptomatic with exercise, and have no neurocognitive deficits (memory loss, concentration problems, fatigue, fogginess, confusion).

Medical Home

The most underserved population in health care today is adolescents. In many instances, their only contact with the medical system is the PPE. Ideally, the PPE would be performed in the medical home to provide the comprehensive care required for this population relating to a myriad of risk factors that affect more than their lives as athletes.

SUMMARY

- A PPE is should be performed on all patients with the goal of promoting overall wellness through physical exercise; it is not performed primarily to disqualify an athlete.
- Ideally, an entire PPE should be performed by a single physician in the office setting.
- Sudden cardiac death in young athletes is a rare event, but a positive cardiac history should be thoroughly evaluated.
- The musculoskeletal history and physical examination are the best ways to discover orthopedic problems.
- Concussion, heat injury, and use of nutritional supplements are topics that need to be discussed and emphasized during the PPE.

Clearance for Return to Play

Name _____ Sex _____ Age _____ DOB _____

☐ Cleared without restriction

☐ Cleared with recommendations for further evaluation or treatment:

_____

_____

_____

_____

☐ Not cleared for:

☐ All sports. Reason _____

☐ Certain sports. Reason _____

Recommendations: _____

_____

EMERGENCY INFORMATION

Allergies: _____

Other information: _____

Immunizations (eg, tetanus/diphtheria; measles, mumps, rubella; hepatitis A, B; influenza; poliomyelitis; pneumococcal; meningococcal; varicella)

☐ Up to date *(see attachment documentation)*

☐ Not up to date. Specify: _____

_____

Name of physician *(print or type)* _____ Date _____

Figure 17-1 Sample clearance for return to play.

TOOLS FOR PRACTICE

Engaging Patient and Family

- *Sports and Your Child* (handout), American Academy of Pediatrics (patiented.solutions.aap.org)
- *Sports Success Rx! Your Child's Prescription for the Best Experience: How to Maximize Potential and Minimize Pressure* (book), American Academy of Pediatrics (shop.aap.org)

Medical Decision Support

- *Preparticipation Physical Evaluation Forms* (forms), American Academy of Family Physicians, American Academy of Pediatrics, American College of Sports Medicine, American Medical Society for Sports Medicine, American Orthopaedic Society for Sports Medicine, and American Osteopathic Academy of Sports Medicine (www.aap.org/en-us/about-the-aap/

Committees-Councils-Sections/Council-on-sports-medicine-and-fitness/Documents/PPE-4-forms.pdf)

AAP POLICY

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Chapter 18

PEDIATRIC IMAGING

Terry L. Levin, MD

IMAGING MODALITIES

With the advent of new technologies in radiology, the choices of imaging modalities available to the physician have become increasingly complex. Selecting the best imaging modality depends on the clinical question at hand. The more focused the question, the clearer the choice of imaging technique.

The initial evaluation of a child often begins with a plain radiograph. Whenever possible, this should be performed in the radiology department rather than by portable units because patient positioning and technique, which affect the quality of the final radiograph, are better managed in the department. Findings on the plain radiograph will often indicate whether further imaging is needed and in many cases will dictate the choice of imaging modality, whether fluoroscopy, ultrasound (US), computed tomography (CT), magnetic resonance imaging (MRI), or nuclear scintigraphy.

Newer, more efficient generations of CT scanners have resulted in a significant increase in the use of CT imaging in the United States. CT imaging accounts for most medically related exposures to ionizing radiation. The Society of Pediatric Radiology has instituted the ALARA (*a*s *l*ow *a*s *r*easonably *a*chievable) principle, by which participating institutions agree to modify CT imaging parameters, modify protocols, and improve patient shielding to reduce patient exposure to ionizing radiation. Additional innovations already adopted by some institutions include the radiation dose passport, a document carried by the parent that records a child's radiation exposure much like a vaccination record.

Fluoroscopy

Fluoroscopy provides real-time evaluation of the airway and of the gastrointestinal (GI) and genitourinary (GU) tracts. In patients with possible tracheomalacia, dynamic changes in airway diameter can be identified with fluoroscopic technique. The upper GI series, with or without small bowel follow-through, allows assessment of swallowing function, esophageal and GI motility, gastroesophageal reflux, and position of the duodenojejunal junction. The small bowel follow-through can evaluate small bowel abnormalities, particularly in children with inflammatory bowel disease. Similarly, the colon is well evaluated by fluoroscopy-guided contrast enemas. Fluoroscopic voiding cystourethrography is useful in evaluating the bladder and urethra and in assessing for vesicoureteral reflux in children with urinary tract infections. Videofluoroscopy allows studies to be replayed and analyzed at a later time. The length of the fluoroscopic procedure determines the radiation dose. Use of pulse fluoroscopy, rather than continuous fluoroscopy, limits dose exposure.

Ultrasound

US is the initial imaging modality of choice when evaluating a child because it imparts no radiation. Additionally, US requires no patient sedation and can be performed at the patient's bedside if necessary. US is limited by body habitus and overlying bowel gas or air. Because the quality of the images depends on the skill of the US operator, the operator must be trained and experienced in working with children. In the GI tract, US is particularly useful in diagnosing pyloric stenosis, appendicitis, and intussusception. It may also be used to assess bowel wall thickening in cases of inflammatory bowel disease and is far superior to CT in determining whether pleural fluid contains debris or loculations in cases of empyema. US is effective in evaluating the GU system and biliary system as well as the neonatal brain and spine. Doppler US has proved useful in evaluating the renal arteries in children with hypertension, in evaluating vascular

and nonvascular lesions, in assessing for ovarian and testicular flow abnormalities, and in determining vessel position and patency. In patients with liver or renal transplants, Doppler US is essential in evaluating flow within the transplanted organ. Contrast agents for US, which consist of microbubbles and have been used in the evaluation of vesicoureteral reflux, have not yet gained wide acceptance.

Computed Tomography

CT is based on a volumetric acquisition of information derived from differential tissue absorption of ionizing radiation. Helical CT significantly shortens image time, and coronal and sagittal reconstructed images are possible. Three-dimensional reconstructions can be obtained with multidetector CT and are effective in cardiac imaging and in evaluating the airway and skeletal system. The newer-generation CT scanners allow increased speed of scanning so that motion artifact is reduced, and a single breath-hold may be sufficient to image large areas. This feature is particularly helpful in young children. CT is not limited by overlying gas and provides a larger field of view than US. It is the imaging modality of choice in evaluating the lungs and is far more sensitive in detecting small lung lesions than plain chest radiography. CT is also the initial imaging modality of choice in cases of trauma, because it may detect organ injury not identified on ultrasound. Newer uses of CT include CT renal angiography for evaluating for renovascular hypertension and CT urography to evaluate renal function and anatomy. Neutral oral contrast agents, which distend the small bowel and provide excellent assessment of the bowel lumen and the bowel wall, are useful in patients with inflammatory bowel disease, particularly Crohn disease.

CT has several limitations. Patients must be cooperative, and sedation may be required in young children. Because it is based on gray-scale analysis, intravenous or oral contrast is often required, particularly in children who have very little body fat. With the advent of newer intravenous contrast agents, the risk for adverse contrast reactions has decreased. However, such reactions may still occur, and informed consent is necessary.

Because of its ready availability and its ability to rapidly acquire images, there has been a significant rise in the use of CT in the past decade in the United States and a trend to use CT scanning as a screening rather than a diagnostic technique. The risk for overuse of CT is significant, however, because CT delivers ionizing radiation, a known carcinogen, to our patients. A single abdominal CT scan may be equivalent to 250 to 500 plain chest radiographs. As a response to the rising use of CT imaging in children, the Alliance of Safety in Pediatric Imaging and the Image Gently campaign were created. As a result, awareness of medical radiation safety has improved. From the referring physician's perspective, CT scans should be obtained when specifically indicated and not used as screening examinations. "The procedure should be restricted to cases where it is specifically indicated, and promises to convey a commensurate benefit in terms of a diagnosis that is difficult to obtain by any other means."Children should be referred to instituitions abiding by the ALARA principle for CT scanning.

Magnetic Resonance Imaging

MRI requires no ionizing radiation and has the advantage of providing multiplanar imaging. The patient must be cooperative, and sedation may be necessary. Examination time is longer than that with a CT scan. Noniodinated contrast agents may be used in select cases and have a low incidence of adverse reactions. MRI provides excellent evaluation of vessels, solid organs, bone marrow, and soft tissues, but it cannot assess lung disease. Cardiac MRI evaluates both cardiac anatomy and cardiac function. MRI provides excellent evaluation of the central nervous system and is the imaging modality of choice to assess the spine, spinal cord, and spinal canal. Magnetic resonance (MR) urography displays urograms of nondilated and dilated collecting systems, and it provides information on both anatomy and function by determining renal transit time. As such, MRI has replaced conventional intravenous pyelograms. MR cholangiography is useful as a noninvasive method of assessing the biliary and pancreatic ducts and is superior to all other modalities in evaluating bony and soft tissue lesions.

MR venography and MR arteriographyprovide information about venous and arterial flow, including assessment of vessel patency, stenoses, lymphovascular malformations, and other abnormalities of both small and large vessels.

Nuclear Scintigraphy

Nuclear scintigraphy has many uses in children. The diisopropyl iminodiacetic acid (DISIDA) scan can assess biliary excretion and gallbladder function and is a useful adjunct to US, which provides only anatomic information. The scintigraphic renogram shows differential renal function that can provide information on the degree of renal parenchymal damage. Additionally, when performed after intravenous furosemide administration, it is helpful in confirming the presence or absence of renal obstruction.

Scintigraphy has many applications in pediatric oncology. Positron emission tomography (PET) is useful in assessing tumor activity, particularly in cases of lymphoma. PET-CT combines both modalities in a fusion image. This combination provides anatomic and functional information and plays an important role in tumor staging, assessing of therapeutic response, and monitoring disease after completion of therapy. Unfortunately, PET-CT delivers a high dose of ionizing radiation. In patients with neuroblastoma, meta-iodobenzylguanidine (MIBG) scanning is sensitive in detecting tumor activity in primary and metastatic foci and is effective in evaluating patients for tumor recurrence. Thallium (Tl-201) scanning has been used to assess therapeutic response in patients with osteogenic sarcoma and Ewing sarcoma. Decreased tumor uptake of thallium after chemotherapy indicates a favorable response to therapy.

SYSTEMS APPROACH

Chest

The initial evaluation of the chest begins with a plain radiograph. Pneumonia, atelectasis, cardiac enlargement, pleural effusion, chest wall and ribs, and

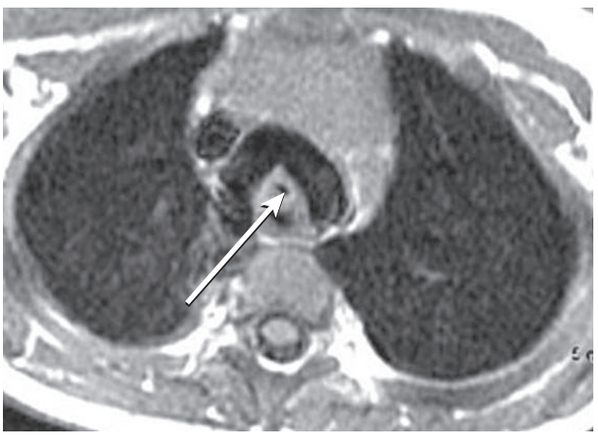

Figure 18-1 T1-weighted axial magnetic resonance image clearly demonstrates a double aortic arch. Note the narrowed trachea *(arrow)*.

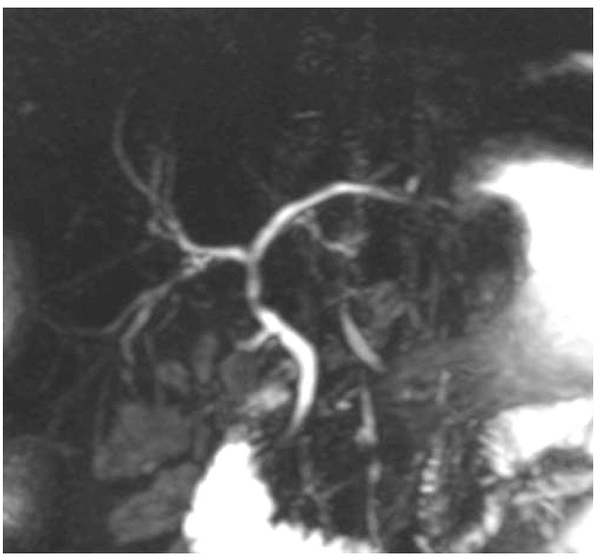

Figure 18-2 Heavily T2-weighted maximal image projection from a magnetic resonance cholangiogram demonstrates the normal biliary tree.

adenopathy can be assessed by plain radiograph. Assessment for an aspirated foreign body is best performed with inspiratory and expiratory films of the chest or bilateral decubitus views of the chest. Evaluation for rib fractures should include dedicated oblique views of the ribs. Parenchymal and airway diseases, including congenital, neoplastic, infectious, or inflammatory conditions of the lung, are best evaluated by noncontrast CT. With current software, 3-dimensional endoscopic reconstructions of the airway may be obtained. Intravenous contrast-enhanced CT scans of the chest provide further information on pleural enhancement, loculation, or thickening in the setting of empyema, extent of hilar and mediastinal adenopathy in patients with neoplastic disease, and presence of vascular anomalies. Congenital abnormalities of the aorta and its branch vessels can be evaluated by either contrast-enhanced CT or MRI (Figure 18-1). Cardiac disease is best assessed by echocardiogram or MRI.

Abdomen

The initial evaluation of the liver, spleen, and pancreas is best performed by US. Masses, vascular abnormalities, and diffuse parenchymal abnormalities may be identified on US. Infectious processes such as abscesses may also be identified. Although liver and splenic laceration may be imaged by US, contrast-enhanced CT is the study of choice when assessing for injury after abdominal trauma.

US is also the best method of assessing the gallbladder and biliary ductal anatomy. Gallstones not visualized on CT will be evident on US, and biliary duct dilation, stones, or masses can be identified. Findings of cholecystitis, including gallbladder distention, wall thickening, and edema, will be identified. Biliary function, however, is best evaluated with nuclear scintigraphy. Additionally, nuclear scintigraphy is the study of choice in diagnosing biliary atresia. MR cholangiography is a noninvasive method that provides excellent visualization of the biliary ducts (Figure 18-2).

Gastrointestinal Tract

Contrast studies are the first choice in evaluating the bowel after a plain radiograph has been taken to assess the abdominal bowel gas pattern. Barium or water-soluble contrast agents are administered orally or by feeding tube. In the esophagus, intrinsic lesions such as stenoses, fistulas, rings, foreign bodies, and esophagitis are well defined. Extrinsic lesions such as vascular rings or slings have a characteristic appearance (Figure 18-3). Motility disorders and gastroesophageal reflux may also be diagnosed. Contrast studies also provide information on intrinsic or extrinsic abnormalities of the stomach, including masses and ulcer disease, and are useful in evaluating the integrity of the gastroesophageal junction in children after fundoplication.

In children with suspected possible malrotation, an upper GI series will define the location of the duodenojejunal junction and confirm or exclude proximal small bowel distention. Contrast enema may be performed at the same time to define the position of the cecum in unclear cases. The relationship of the superior mesenteric artery and vein on US has been used to diagnose malrotation; however, because of false-positive and false-negative results, the upper GI series is the study of choice. Midgut volvulus can be diagnosed by US as a *whirlpool sign,* indicating that the torsed bowel will be demonstrated on color Doppler scanning. US has replaced the upper GI series for the evaluation of the pylorus in cases of suspected pyloric stenosis. The elongated and thickened pyloric muscle characteristic of pyloric stenosis is readily identifiable by US (Figure 18-4).

Small bowel disease, particularly inflammatory bowel disease, is best evaluated by upper GI series and small bowel follow-through or CT enterography. Terminal ileal strictures, fistulas, and mesenteric

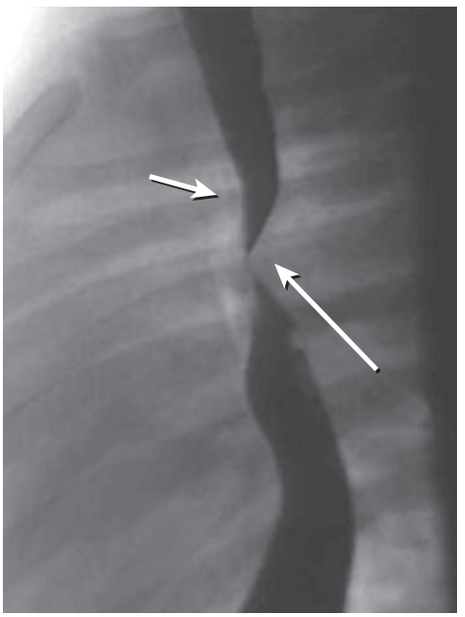

Figure 18-3 Lateral view from a barium esophagram demonstrates an extrinsic impression on the posterior aspect of the esophagus *(long arrow)* and the anterior aspect of the esophagus *(short arrow)*. The finding is consistent with a vascular ring.

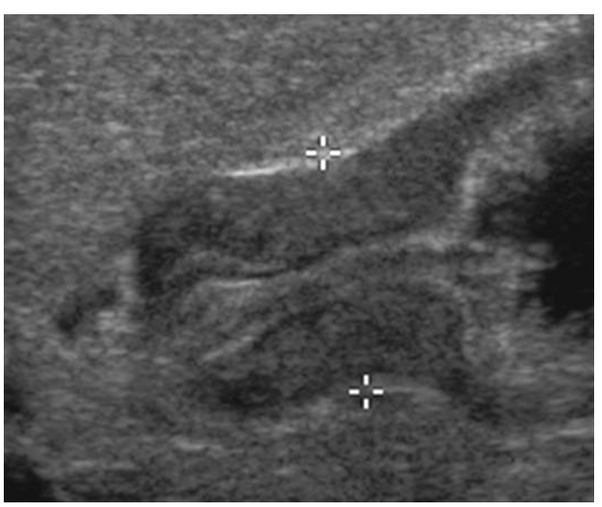

Figure 18-4 Longitudinal US image demonstrates the characteristic thickened and elongated pyloric muscle of pyloric stenosis. Calipers delineate the diameter of the pylorus.

infiltration can be clearly diagnosed on delayed images focused on the right lower quadrant. CT is helpful in evaluating for associated abscesses. The small bowel follow-through also is effective in evaluating for small bowel polyps, although with the introduction of newer neutral oral contrast agents, the role of CT will likely increase. Nuclear scintigraphy is the method of choice in diagnosing Meckel diverticulum. In cases of

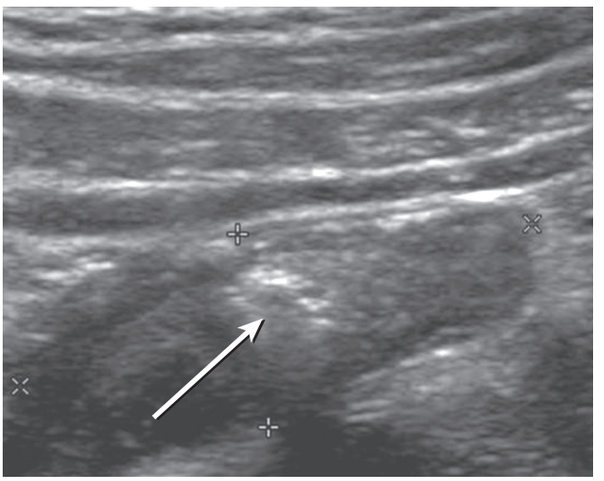

Figure 18-5 US image of an inflamed appendix. Note the appendicolith *(arrow)*. Calipers delineate the inflamed appendix.

possible intussusception, the imaging evaluation should begin with supine, prone, and decubitus views of the abdomen in an attempt to identify a filling defect in the transverse or ascending colon. If intussusception is suspected on plain radiograph, then US confirmation may be obtained. In cases in which an intussusception is present, a multilayered, masslike structure will be located in the abdomen. US has the advantage of providing further information, such as the presence or absence of ascites or a lead point and the presence or absence of vascularity within the intussuscipiens and intussusceptum. Air-reduction enema has replaced contrast enema reduction of intussusception. Air is insufflated in a retrograde fashion into the rectum under fluoroscopic guidance. A pressure valve may be used to ensure that the insufflated pressure does not exceed 120 mm Hg.

The diagnosis of appendicitis can be difficult. Several imaging choices are available to aid in the diagnosis, and many opinions have been given on which modality is best. In a thin, cooperative child, US is an effective method of identifying the inflamed appendix, which will appear as a thick-walled, noncompressible structure with increased vascularity on Doppler US (Figure 18-5). US may also demonstrate the presence of an abscess or appendicolith. Lack of visualization of the appendix does not exclude appendicitis. Recent studies have found that US provides a high degree of diagnostic accuracy in patients with clinical findings suggestive of appendicitis, with a sensitivity of 86%, a specificity of 95%, a positive predictive value of 91%, a negative predictive value of 92%, and a diagnostic accuracy of 92%. Many authors suggest that US be used as the primary imaging modality in evaluating for appendicitis. In cases in which US is not diagnostic, CT with both oral and intravenous contrast can be used. Other authors support the use of contrast-enhanced CT, with reported sensitivity and specificity of 96.5% and 98%, respectively, as the initial imaging

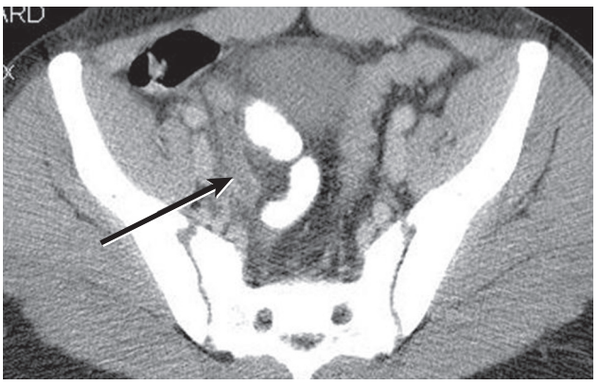

Figure 18-6 Transverse contrast-enhanced CT scan of a thickened, nonruptured inflamed appendix. A blind-ending, thickened loop of enhancing bowel is present *(arrow)*.

technique to diagnose appendicitis. Some authors advocate a focused CT scan to reduce radiation exposure, whereas others avoid oral contrast and perform a CT scan after rectal contrast. Contrast-enhanced CT imaging characteristics of acute appendicitis include an enhancing blind-ending structure near the cecum (Figure 18-6). Associated abscesses, periappendiceal stranding, appendicolith, and free air can also be readily identified. Visualizing a normal appendix reliably excludes appendicitis.

Recent articles in the surgical literature note that more than half of patients with suggested appendicitis undergo imaging. In many cases, imaging findings provide little increase in diagnostic accuracy compared with a treating surgeon's clinical examination. Even though imaging may aid in difficult cases, appendicitis remains a clinical diagnosis, and imaging may contribute to delay in treatment and subsequent appendiceal rupture.

Patients with ruptured appendicitis, recurrent fever, and possible interloop abscesses are best assessed by CT. Ultrasound may also be helpful, although air-filled loops may obscure underlying pathologic anomalies or underestimate extent of abscess or phlegmon formation. In cases of perforated appendicitis, CT-guided abscess drainage may avoid surgery.

The colon may be evaluated by contrast enema. This approach is effective in determining the cause of abdominal distention in a neonate with a distal bowel obstruction and is also useful in identifying a transition zone in older patients with Hirschsprung disease.

Genitourinary Tract

The initial assessment of the pediatric GU tract begins with US. The kidneys and bladder are well assessed for hydronephrosis, infectious processes, masses, stones, and anatomic abnormalities. Further evaluation for vesicoureteral reflux and structural anomalies of the urethra and upper tracts may be performed by voiding cystourography (Figure 18-7).

In the case of a renal mass identified on US, US may assess for the presence of tumor thrombus within the ipsilateral renal vein and the presence of tumor in the

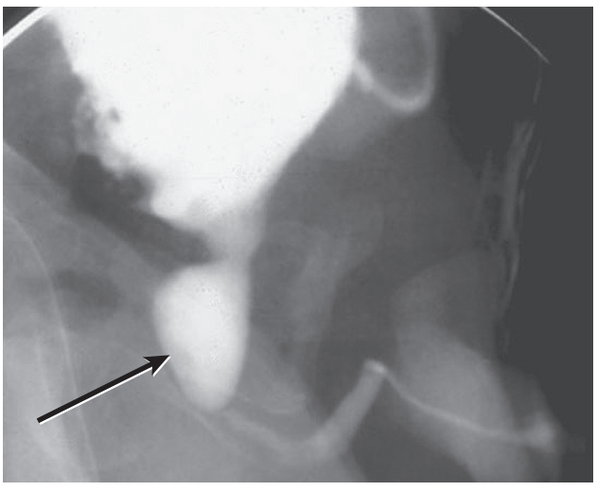

Figure 18-7 Voiding cystourethrogram reveals a trabeculated bladder and a dilated posterior urethra *(arrow)*. Findings are consistent with posterior urethral valves.

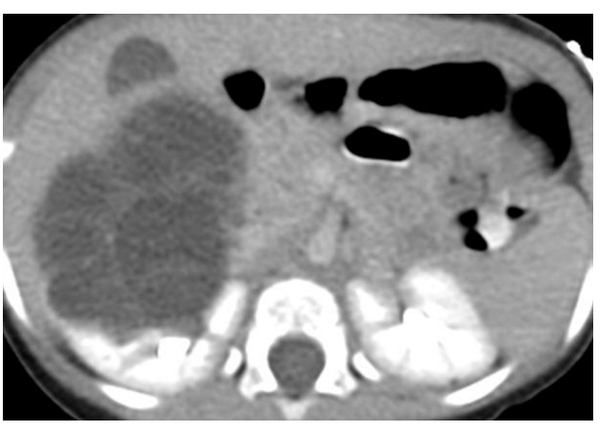

Figure 18-8 Contrast-enhanced CT scan of a Wilms tumor.

contralateral kidney. CT is the study of choice to evaluate for lung metastases. Additionally, contrast-enhanced CT will provide information on tumor extent and vascularity and will also evaluate the contralateral kidney (Figure 18-8). MRI will provide similar information on tumor extent and vascularity and the status of the contralateral kidney. MRI provides superior evaluation of vascular invasion into the inferior vena cava or renal veins but is not effective in assessing for the presence of lung metastases. In the case of neuroblastoma, MRI provides superior evaluation of intraspinal extension and bone marrow involvement.

In patients with renovascular hypertension, Doppler US can detect anatomic abnormalities and provide information on flow velocities and resistive indices in the renal arteries and their branch vessels. However, the examination requires breath-holding and is difficult to perform in small children. A normal result

Figure 18-9 Coronal computed tomography (CT) scan from a CT renal angiogram. Note normal renal arteries.

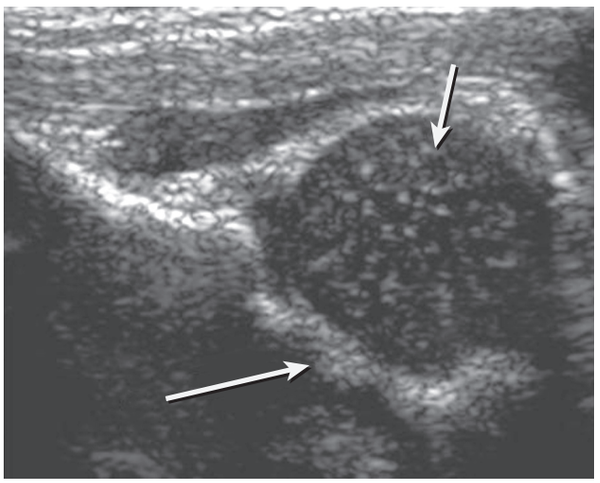

Figure 18-10 Longitudinal image from a hip ultrasound. The cartilaginous femoral head *(short arrow)* is well seated in the acetabulum *(long arrow)*.

in young children and infants does not exclude renal artery stenosis. CT renal angiography provides excellent anatomic detail of renal artery abnormalities, particularly when images are reconstructed in multiple planes (Figure 18-9). The renal arteries can also be well evaluated by MR angiography, which avoids ionizing radiation.

US may be used to evaluate for pyelonephritis. However, contrast-enhanced CT clearly demonstrates areas of decreased renal perfusion secondary to edema in patients with pyelonephritis in whom US is equivocal. Dimercaptosuccinic acid (DMSA) nuclear scintigraphy is also effective in diagnosing the parenchymal defects characteristic of pyelonephritis. Although CT will demonstrate the extension of an inflammatory process into the perirenal space, nuclear scintigraphic information is limited to abnormalities within the renal parenchyma. Upper tract stone disease is best assessed by US. Noncontrast CT imaging has the advantage of identifying ureteral stones that may not be detected on US because of overlying bowel gas. Renal function may be evalutaed by nuclear scintigraphy, although MR urography has the advantage of providing information on both anatomic features and renal function.

Bone

Evaluation of the skeletal system begins with a plain radiograph. This method is effective in defining fractures, joint effusions, gross marrow infiltration, extent of scoliosis, and healing areas of bone infarction. In children who are suspected of having nonaccidental trauma, skeletal surveys are indicated and include the evaluation of the skull, spine, ribs, pelvis, long bones, hands, and feet by focused, high-detail images of individual bones. These images are evaluated for the presence of classic metaphyseal injuries highly suggestive of abuse, fractures at different stages of healing, and unusual fractures. Skeletal surveys are also useful in evaluating patients with bone dysplasias.

Musculoskeletal US is useful in evaluating infants with developmental dysplasia of the hip (Figure 18-10), in assessing for joint effusions, and in directing the aspiration of the effusions under US guidance. US may also be used to evaluate for subperiosteal collections in cases of osteomyelitis. Ultrasound can image fractures of nonossified cartilage and epiphyses, such as salter fractures of the toddler elbow. It may also be useful in evaluating joints for hyperemia and joint effusions in cases of juvenile inflammatory arthritis.

MRI has the advantage of being able to define marrow, cortical, and soft tissue involvement and has become the imaging modality of choice in evaluating for skeletal lesions and osteomyelitis (Figure 18-11). MRI also has the ability to evaluate cartilage and is particularly useful in the skeletally immature child.

The use of CT in assessing the pediatric musculoskeletal system is limited. In the setting of trauma, CT reconstructions may be used to determine the degree of malalignment and displacement of fracture fragments at an articular surface. Additionally, in children with developmental dysplasia of the hip after varus derotational osteotomy and casting, CT best determines the position of the femoral head relative to the acetabulum. Scanograms to evaluate for leg-length discrepancy can now be performed with a CT scout view, rather than plain radiographs. The chest CT with 3-dimensional reconstruction can vividly identify rib fractures, which may be missed on plain film imaging.

Bone scintigraphy is useful in cases of possible osteomyelitis but can be limited by the normally increased radiotracer uptake seen in the metaphyses of growing bones, which may obscure areas of abnormally increased uptake in sites of metaphyseal osteomyelitis, a problem not encountered with MRI. Nuclear scintigraphy may be useful in cases of possible

Figure 18-11 T2-weighted magnetic resonance image of the leg demonstrates high signal within the fibular marrow with adjacent soft tissue changes. The findings are consistent with osteomyelitis.

child abuse and may detect rib fractures not evident on plain radiographs; however, it is less effective in identifying classic metaphyseal injuries and skull fractures. Nuclear scintigraphy is also helpful when multifocal bone disease is suggested, such as with malignancy or multifocal osteomyelitis.

Nervous System

Central nervous system imaging is performed by US, CT, or MRI. In the neonate or infant with an open fontanelle, US is an excellent method of imaging the brain. Repeat US studies can be performed to follow intracranial hemorrhage and ventricular size. Areas of the brain not well visualized by US and better evaluated by CT or MRI include the extra-axial spaces, the brain surface, and the frontal and occipital poles. In neonates, assessment of the spinal cord can be performed with US, provided that the posterior elements have not fused and an acoustic window is present. US is effective in determining the position of the conus in an infant with a sacral dimple. It may also identify intraspinal abnormalities such as lipomas. Findings may be confirmed with MRI.

The neonatal brain also may be assessed by CT or MRI. Both modalities demonstrate similar findings, with greater interobserver agreement with MRI. Additionally, MRI provides no ionizing radiation to the patient. In older children, MRI has the same advantages over CT and more clearly demonstrates myelination abnormalities, edema, subdural hemorrhage, and infarcts. MRI is the study of choice in evaluating the spine, spinal cord, and spinal canal in children because the posterior elements have fused. Newer uses of MRI include diffusion-perfusion imaging and MR spectroscopy.

Although CT imaging of the brain has been largely replaced by MRI, it remains the most sensitive modality to detect subarachnoid blood and calcifications, which may be present in congenital lesions such as TORCH (*t*oxoplasmosis, *o*ther agents, *r*ubella, *c*ytomegalovirus, *h*erpes simplex virus) infections and tuberous sclerosis. It remains the imaging modality of choice in children with acute, unstable head trauma. In addition, CT is the study of choice in evaluating the temporal bone and in assessing for fractures of the face and spine. Three-dimensional reconstruction can greatly enhance the recognition of skull injuries compared with routine bone windows.

CONCLUSION

Although newer imaging modalities now offer more detailed anatomic and functional information, the many imaging choices available to the physician can be overwhelming. The choice of examination depends on the question that the physician hopes to answer. The more focused the question, the clearer the choice of imaging modality. Radiation dose and risk for sedation, if required, and the ability of the child to undergo the examination must be considered. Ultimately, the pediatric radiologist should be consulted to help guide the physician through the myriad imaging options.

TOOLS FOR PRACTICE

Engaging Patient and Family

- *Pediatric Abdominal Ultrasound*, (fact sheet), Radiology Info (www.radiologyinfo.org/en/info.cfm?PG=abdomus-pdi&bhcp=1)
- *Pediatric Computed Tomography (CT)* (fact sheet), Radiology Info (www.radiologyinfo.org/en/info.cfm?PG=pedia-ct)
- *Pediatric Nuclear Medicine* (fact sheet), Radiology Info (www.radiologyinfo.org/en/info.cfm?PG=nuclear-pdi)
- *Radiology and Medical Imaging* (Web site), Cincinnati Children's Hospital Medical Center (www.cincinnatichildrens.org/service/r/radiology/default/)
- *What Is a Pediatric Radiologist?* (fact sheet), American Academy of Pediatrics (healthychildren.org/English/family-life/health-management/pediatric-specialists/Pages/What-is-a-Pediatric-Radiologist.aspx)

SUGGESTED READINGS

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SECTION TWO

Preventive Pediatrics

Chapter 19
ENVIRONMENTAL HEALTH: THE ROLE OF THE PRIMARY CARE PHYSICIAN

Katherine M. Shea, MD, MPH; Sophie J. Balk, MD

INTRODUCTION

Health is determined by complex and ongoing interactions between genes and the environment—the classic nature/nurture dialog in pediatrics. Throughout history, the most dramatic advances in population health have been associated with improving the environment—safe drinking water, safe and abundant food, adequate shelter, clean indoor and outdoor air. In the 20th century, progress in microbiology, biochemistry, and genomics produced advances in combating many diseases, simultaneously causing an overemphasis on the "nature" of disease and a neglect of the "nurture" of health in the form of safe and healthy environments. Since the maturation of a robust movement of pediatric environmental health (PEH) in the 1990s, attention is returning to environmental components of children's health and disease. Genes, proteins, and microbes operate within the context of not just the human body, but also the greater environment. For children, that environment includes air, water, food, shelter, and consumer goods, as well as the maternal environment of the womb, breast milk, and even the preconception environment of each parent (see Box 19-1). The conditions and integrity of these environments affect the expression and success of genes and are, therefore, within the purview of all pediatricians.

In the field of environmental health, the environment is typically categorized and studied according to the specific types of media that carry environmental hazards (eg, air, water, soil, and food), or by settings where exposures occur (eg, places children live, learn, play, and work). At the level of population health, the environment includes ecosystems (from pristine forests to urban landscapes) and natural biogeochemical cycles (from the nitrogen cycle to the climate system). No matter how the physical environment is defined, it is clear that humans are powerful in our ability to affect the integrity of the environment and how it interacts with genes.

PEH is a specialty area because children and adolescents are growing and changing, as are their settings and vulnerabilities, and they are often more severely affected by unhealthy environmental conditions compared to other age groups (see Box 19-2).

A life-stage approach to risk and prevention considers environmental exposures from preconception through completion of development (in the mid-twenties) and lends itself to preventive practice. Each life stage has distinct parameters of exposure, physiology, and susceptibility that affect health outcomes resulting from interaction with environmental hazards. In some cases, disease occurs shortly after the exposure and causality is obvious (as with acute chemical poisonings or radiation burns). After other environmental exposures (as with radon or asbestos), expression of adverse health outcomes is delayed, sometimes for years or even decades. Some exposures

BOX 19-1 Prenatal Influences: Maternal Exposures and Body Burden, Paternal Exposures, Epigenetic Phenomena

Unique to pediatric environmental health is the need to consider the effect of maternal and paternal exposures on the preconception environment, and of previous and concurrent maternal exposures on the prenatal environment. Maternal exposures to certain pollutants before and during pregnancy can adversely affect fetal growth and development. Some toxicants are stored in the body over time, creating a high maternal body burden presented to a growing fetus. In general, the higher the body burden, the higher the prenatal exposure. Well-documented examples include the neurotoxicants polychlorinated biphenyls (PCBs), lead, and mercury.

Paternal preconception exposures are also linked to an increased risk of harm to children. One mechanism of exposure under intense investigation is related to epigenetic changes that affect gene expression but not nucleotide sequence. Some epigenetic changes can become transgenerational. Environmental hazards suspected of causing epigenetic changes in the zygote include ionizing radiation, organic solvents, and pesticides.

Derived from American Academy of Pediatrics Council on Environmental Health. Individual susceptibility to environmental toxicants. In: Etzel RA, Balk SJ, eds. *Pediatric Environmental Health.* 3rd ed. Elk Grove Village, IL: American Academy of Pediatrics; 2012:27–38

BOX 19-2 Children Are Uniquely Vulnerable to Environmental Hazards

- Children are constantly growing and changing physically and metabolically.
- Their organs and systems are immature and susceptible to disruption.
- Their natural behaviors, curiosity, and location in the world often increase their exposures to environmental hazards.
- They have long lifetimes in which to express and experience environmental disease.
- They do not have political power with which to protect themselves from environmental harms and must rely on adults for protection.

that occur early in life lead to changes in structure and function of body systems; these may cause permanent deficits or predispose to adult-onset illness. Environmental conditions also play a causal role in epidemics seen in children: obesity, diabetes, asthma, allergies, and neurodevelopmental disorders. The pediatric traditions of prevention and anticipatory guidance provide natural approaches to integrating environmental disease prevention into practice. Furthermore, the emphasis in pediatrics on optimizing social, behavioral, and educational environments can be extended easily to counseling parents and communities on optimizing and protecting all aspects of the physical environment (see the Environmental Health Challenges section).

This chapter addresses approaches to prevention, recognition, and treatment of environmental illness in children, from the traditional exposure-disease model to the more universal primary prevention and precaution model. The examples chosen are a few of many possible. Physicians are encouraged to explore the tools, resources, and references provided for more comprehensive descriptions and details.

ENVIRONMENTAL HAZARD APPROACH TO PEDIATRIC ENVIRONMENTAL HEALTH

Environmental hazards or threats can be categorized by type (eg, heavy metals, manmade chemicals, physical hazards, biological hazards, social/behavioral hazards) (Table 19-1). While some hazards cause distinct diseases or syndromes, others form part of the risk profile for arrays of illnesses and conditions. The more low-dose, chronic, or intermittent the exposure, the more difficult it is to link definitively an exposure to an adverse health outcome. Exposure can occur via many routes (eg, ingestion, inhalation, or dermal) and media (eg, air, water, or soil). Some of these can be controlled at the individual level and others only at the societal level. A few well-studied examples of hazards and health outcomes are described briefly in the following text.

Heavy Metals

Lead poisoning is the classic heavy metal hazard. An understanding of children's special vulnerabilities to lead evolved through the 20th century as knowledge accumulated about the many harms suffered by exposed children. Health effects range from catastrophic brain injury and death resulting from acute high-dose exposure to decreased intellectual capacity, attention-deficit/hyperactivity disorder (ADHD), lower academic achievement, and other effects from lower-dose exposure. Lead also illustrates the range of sources (in the United States, primarily paint chips and dust, but also imported jewelry, spices, and historically leaded gasoline); routes of exposure (in utero, inhalation, ingestion); the increased risk of exposure through normal childhood behaviors (hand-mouth/object-mouth behavior, nonnutritive ingestion); and vulnerability because of immature physiology. These behavioral and physiologic characteristics result in children having higher internal doses, as well as different and permanent harms compared to adults. Eliminating sources can prevent exposures and can thus prevent lead poisoning. See Chapter 283, Lead Poisoning, for more information.

An understanding of *mercury*, (the "new lead") has followed a similar but more rapid evolution. In Minamata Bay in Japan in the 1950s, prenatal exposure to high doses of methylmercury, an organometallic compound, in contaminated fish resulted in death or severe neurologic disability. In developed countries today, consumption of fish containing lower amounts of methylmercury (compared with Minamata Bay's contamination levels) by mothers before and during pregnancy, leading to subtle brain damage in the fetus, is now the major concern about mercury. Prevention is possible if heavily mercury-contaminated fish is limited in the diets of women of childbearing age and young children.

Manmade Chemicals

More than 80,000 industrial and commercial chemicals have been synthesized globally in the latter half of the 20th century, and that number increases daily. However, their toxicities are largely unstudied. With the rapid advances in analytical chemistry over past decades, it is possible to measure very low levels of chemical pollutants in water, air, soil, food, animals, and people. Contamination of all media by a wide variety of chemicals is documented, but, for most chemicals, we have little knowledge of the effect of exposure on human health. For example, despite incomplete scientific information in humans, including children, there is increasing concern about health effects of the class of plasticizers known as *phthalates,* and a plastic building block*, bisphenol A* (BPA) (see Box 19-3).

When there is abundant scientific information, it is found that children are among the most susceptible to harm. For example, pesticides are among the most studied of industrial chemicals. A few have been quite thoroughly evaluated for harm to human health in general and children in particular. Chlorpyrifos, an organophosphate insecticide, was withdrawn voluntarily from all household use in the United States in 2001 because of concern raised by numerous studies. Research documented ubiquitous pediatric exposure; epidemiologic data and studies in animals identified chlorpyrifos as a neurotoxicant to the developing brain. Other pesticides (both restricted and

Table 19-1 Examples of Specific Environmental Hazards

HAZARD CATEGORY WITH SPECIFIC EXAMPLES	MAJOR SOURCES	MAJOR ROUTES OF EXPOSURE	TARGET ORGAN/ SYSTEM
METALS			
Arsenic	Drinking well water, soil (especially around old structures made from wood treated with Chromated Copper Arsenate [CCA])	Ingestion, inhalation	Known carcinogen, also affects GI tract, cardiovascular, hematologic, neurologic systems, skin, and liver
Lead	Leaded paint and dust, ceramic glazes, imported jewelry, leaded gasoline (as of 2015, sold only in Algeria, Iraq, and Yemen),[a] drinking water	Ingestion, inhalation, transplacental	CNS, hematologic, GI tract, cardiovascular, kidney
Methylmercury	Long-lived, predatory fish, marine and fresh water	Ingestion, transplacental	Known teratogen at high doses, also affects CNS
SYNTHETIC CHEMICALS			
Bisphenol A (BPA)	Consumer products, including certain hard plastic bottles	Ingestion	Endocrine system
Pesticides	Food, air from drift, drinking water, home and yard use	Ingestion, inhalation, dermal absorption, transplacental	CNS, endocrine, acute poisoning, carcinogens (depending upon chemical and exposure)
Polychlorinated biphenyls (PCBs)	Environmentally persistent, found in food, plants, and soil	Ingestion, transplacental	CNS, endocrine
PHYSICAL			
Heat	Ambient temperatures, inadequate climate control in enclosed spaces	Direct, whole body	Water/electrolyte homeostasis
Ionizing radiation—radon	Poorly sealed basements, drinking water	Inhalation, ingestion	Known carcinogen
Nonionizing radiation—ultraviolet	Sun exposure, tanning beds	Direct dermal, eyes	Skin, eyes, immune system, known carcinogen
Noise	Traffic, airplanes, music, machinery, medical equipment in intensive care units	Direct to hearing apparatus	Otologic, CNS, cardiovascular
BIOLOGIC			
Aflatoxin	Wheat, corn, nuts, nut butters	Ingestion	Liver, known carcinogen, acute poisoning
Vector-borne	Outdoor activities	Dermal	Variable
SOCIAL/BEHAVIORAL			
Carbon monoxide	Poorly maintained or ventilated fuel-burning appliances	Inhalation	Hematologic, CNS
Secondhand tobacco smoke (SHS)	Maternal and household smoking	Inhalation, transplacental	Pulmonary, immune, cardiovascular, SIDS, known carcinogen, adverse pregnancy outcomes

CNS, central nervous system; *GI,* gastrointestinal; *SIDS,* sudden infant death syndrome.
[a]United Nations Environment Programme. *Leaded Petrol Phase-out: Global Status as of January 2015*. Available at www.unep.org/Transport/new/PCFV/pdf/Maps_Matrices/world/lead/MapWorldLead_January2015.pdf. Accessed November 1, 2015.
This table contains representative examples in each category and only the major sources, routes of exposure, and adverse effects. For more comprehensive information readers should explore additional resources including the AAP Pediatric Environmental Health Handbook; Etzel RA, Balk SJ, eds. American Academy of Pediatrics. *Pediatric Environmental Health.* 3rd ed. Etzel RA, Balk SJ, eds. Elk Grove Village, IL: American Academy of Pediatrics; 2012.

still in use) have been associated with adverse neurodevelopmental effects, increased cancer risk, birth defects, pregnancy loss, disruption of endocrine and immune systems, and adult-onset neurodegenerative illness (perhaps beginning with childhood exposures). As with lead, our understanding of the effects of chemicals has improved through studying individual classes of chemicals, such as the organophosphates. The more we learn, the more we understand that there is often not a "safe" level of exposure for children. Eliminating or minimizing exposures is the best way to protect children's health.

BOX 19-3 Phthalates and Bisphenol A

Phthalates are chemicals added to plastics and other products to impart flexibility and durability; *bisphenol A* (BPA) is a fundamental building block of plastic. Phthalates are found in consumer products such as children's toys, food packaging, vinyl flooring, wall coverings, and personal care products. Phthalates also are used in medical devices such as intravenous tubing. BPA is found in linings of food cans, including those for ready-to-feed infant formulas, and in hard plastics made of polycarbonate (found in sports water bottles, water dispensers, and baby bottles). Phthalates are not covalently bound to the plastics and can leach out of products. This may result in exposure through ingestion of foods found in packaging, mouthing of products, or inhalation of dust generated from these products. Young children are likely to have higher exposures because they often mouth toys and other plastic products. Newborns treated in intensive care units may be highly exposed to phthalates when they receive multiple medical therapies. Studies in humans have shown associations of phthalate exposure with endocrine and other outcomes. Studies in animals have shown an association between BPA exposure and adverse reproductive and neurobehavioral effects. Studies in people, although limited, have shown associations between high BPA exposure and heart disease, type 2 diabetes, and abnormal liver tests[a]. The US Centers for Disease Control and Prevention recently measured phthalate and BPA metabolite levels in urine specimens from a nationally representative sample of people aged 6 to 85 years. Results showed that nearly everyone had measurable concentrations of these chemicals in their bodies; children and adolescents had higher levels compared to adults[b]. Because of rising concern about possible adverse health effects, parents can be advised to take the following precautionary measures to limit their children's exposures to potentially harmful plastics[a]:

- Avoid placing plastics in the dishwasher and microwave, since high temperatures may promote leaching.
- Look to recycling labels in the absence of mandatory labeling—#3 plastics *may* contain lead and phthalates, and #7 plastics *may* contain BPA. Choose plastics that are labeled #1, 2, 4, and 5.
- If formula is used, choose powdered rather than prepared canned infant formula.
- Choose unlined stainless steel water bottles over plastic. Consult bottle manufacturers' Web sites to obtain descriptions of the bottles, including whether they contain BPA.
- Consider using glass baby bottles and glass containers for food storage, being mindful of the slight increased risk of injury from breakage.
- Advocate for verifiable and enforceable right-to-know labeling for phthalates and BPA in consumer products and food packaging.

[a]Galvez MP, Forman JA, Graber NM, Sheffield PE, Balk SJ. Hot topics in environmental health. *Contemp Pediatr.* 2009;26:34–47. Available at: contemporary pediatrics.modernmedicine.com. Accessed October 31, 2015.
[b]Centers for Disease Control and Prevention, National Center for Health Statistics. National Health and Nutrition Examination Survey. Available at: www.cdc.gov/nchs/nhanes.htm. Accessed November 1, 2015.

Physical Hazards

The health effects of physical hazards are as variable as the hazards themselves. Noise at very high levels can cause immediate temporary or permanent hearing loss and, at moderate levels, is implicated in poor school performance and information retention. Acute exposure to ionizing radiation, as occurred after atomic bomb exposure, can cause acute radiation poisoning. Increased rates of thyroid cancers were seen in children and adolescents after the Chernobyl disaster. Excessive exposure to ultraviolet rays from the sun or artificial sources, such as tanning beds, increases the risk of skin cancers; exposure occurring during childhood, adolescence, and young adulthood is thought to confer increased risk. Excessive ambient heat can be fatal for a baby left unattended in a closed car or apartment, because babies are less able to regulate body temperature and have no ability to remove themselves from danger. Older children are at increased risk of developing heat exhaustion or heat stroke during heavy exercise or sports activities that are often scheduled during hours of maximum temperatures in the late afternoon. Attention to these and other physical environmental health hazards is within the realm of pediatric practice.

Biological Hazards

This category includes envenomations, toxins, and allergens. In the developed world, cockroach, rodent, and dust mite allergens are major triggers for asthma. This phenomenon exemplifies an environmental aspect of a complex, epidemic disease. Especially in the developing world, aflatoxin exposure from contaminated grains and nuts puts billions of people at increased risk for hepatic cancer after exposures beginning in early childhood.

Behavioral and Social Hazards

Environmental diseases also may arise from habits and activities of others who bring hazards into a child's world. Tobacco use at home by parents, caregivers, and household members places children at risk for hazards, including pregnancy complications, decreased prenatal growth, SIDS, increased acute respiratory infections, and chronic respiratory diseases such as asthma. "Take-home" exposures are chemicals or metals that contaminate a child's environment when brought home on the person or clothing of a parent or household member. The complex mechanisms whereby children come into contact with environmental hazards are entry points for prevention strategies.

BOX 19-4 Examples of Major Environmental Laws

ADMINISTERED BY US FOOD AND DRUG ADMINISTRATION (FDA) (WWW.FDA.GOV/REGULATORYINFORMATION/LEGISLATION/DEFAULT.HTM)

Federal Food, Drug and Cosmetics Act (1938)

Among other provisions, the law authorized the FDA to demand evidence of safety for new drugs, issue standards for food, and conduct factory inspections.

ADMINISTERED BY US ENVIRONMENTAL PROTECTION AGENCY (EPA) (WWW2.EPA.GOV/LAWS-REGULATIONS/LAWS-AND-EXECUTIVE-ORDERS).

Clean Air Act (1970) Amended in 1977 and 1990

The Clean Air Act is the comprehensive federal law that regulates air emissions from stationary and mobile sources. Among other things, this law authorizes the EPA to establish National Ambient Air Quality Standards (NAAQS) to protect public health and welfare, and to regulate emissions of hazardous air pollutants.

Clean Water Act (1972) Amended in 1977

The Clean Water Act establishes the basic structure for regulating discharges of pollutants into the waters of the United States and regulating quality standards for surface waters.

Safe Drinking Water Act (1974) Amended 1996

This law focuses on all waters actually or potentially designated for drinking use, whether from above-ground or underground sources. The act authorizes the EPA to establish minimum standards to protect tap water and requires all owners or operators of public water systems to comply with these primary (health-related) standards.

Resource Conservation and Recovery Act (1976) Amended in 1984 and 1986

The Resource Conservation and Recovery Act gives the EPA the authority to control hazardous waste from "cradle-to-grave." This includes the generation, transportation, treatment, storage, and disposal of hazardous waste.

Toxic Substances Control Act (1976)

The Toxic Substances Control Act (TSCA) of 1976 provides the EPA with authority to establish reporting, record keeping, and testing requirements, and to issue restrictions relating to chemical substances or mixtures. Certain substances are generally excluded from TSCA, including food, drugs, cosmetics, and pesticides.

Food Quality Protection Act (1996)

Some of the major requirements of this act include stricter safety standards, especially for infants and children, and a complete reassessment of all existing pesticide tolerances (the maximum amounts of pesticide residues allowed in foods).

MEDIA AND SETTINGS APPROACHES TO PEDIATRIC ENVIRONMENTAL HEALTH

While the *individual hazards* approach parallels the infectious disease paradigm of agent–susceptible host, the *media* and *settings approaches* define environmental hazards by opportunities or mechanisms of exposure. The *media approach* focuses on environmental media such as water or air. It parallels major environmental laws and regulations (Box 19-4) by categorizing exposures based on the medium carrying a particular pollutant or category of pollutants; (eg, outdoor air, drinking water, recreational water, food, soil, and consumer goods). This approach is particularly useful when exposures are dominated by a single medium (eg, ozone exposure from outdoor air or chlorination byproducts occurring in treated drinking water). Most exposures, however, are from multiple sources and media. Therefore, an integrated approach to protecting children is needed, taking into account all sources and routes, particularly because children's behavior, settings, physiology, and vulnerabilities change over time. The Food Quality Protection Act of 1996 is a landmark law that requires pesticide regulations to be based on a comprehensive evaluation of all children's exposure sources.

A *settings approach* (eg, home, school, play area, public parks, and work sites) offers another way to organize exposures and preventive strategies. Initiatives are underway that seek to prevent unnecessary exposures, emphasizing precaution and prevention. Healthy homes programs aim to minimize as many toxic (or potentially toxic) environmental health hazards as possible, rather than establish "safe" exposure limits usually set by more traditional environmental laws.

A PHYSICIAN'S ROLE IN PREVENTION, DIAGNOSIS, AND TREATMENT

Fortunately, the structure for protecting children from environmental hazards is built into pediatric care. Pediatric primary care already contains the elements needed to address environmental antecedents of disease—a focus on prevention, anticipatory guidance, and family orientation. The challenge for physicians is to integrate the environmental determinants of health more consistently into this pre-existing structure.

Prevention

Because harm from environmental hazards can be severe and lifelong, prevention is the main goal. Many environmental consequences or illnesses are preventable by eliminating exposure. When an environmental hazard is well understood and effective interventions are available, as with lead, mercury, pesticides and secondhand smoke, giving routine anticipatory guidance should be second nature for pediatricians.

BOX 19-5 The Precautionary Principle

The Precautionary Principle as a policy tool was first codified in environmental law in Germany as *Vorsorgeprinzip* (foresight or precautionary principle) in the German Clean Air Act of 1974. It was also included as a key principle in the United Nations Rio Declaration on Environment and Development of 1992. In legal and policy realms, the Precautionary Principle allows for taking protective actions in the face of incomplete scientific information if there is sufficient reason to suspect that a substance is harmful to human health and/or the environment. The European Environment Agency proposed the following definition: "The Precautionary Principle provides justification for public policy actions in situations of scientific complexity, uncertainty, and ignorance, where there may be a need to act to avoid, or reduce, potentially serious or irreversible threats to health or the environment, using an appropriate level of scientific evidence, and taking into account the likely pros and cons of action or inaction."[a] In the clinical setting, this concept is consistent with primary prevention and the avoidance of unnecessary exposures to potentially toxic substances or other environmental hazards. Commonsense applications of the Precautionary Principle in daily activities include using nonchemical pest control strategies (integrated pest management), using glass or crockery instead of plastic containers for storing and microwaving foods, and avoiding chemical air fresheners in homes, child care settings, and schools. Because so many chemicals have not been tested for toxicity, the Precautionary Principle suggests that avoiding exposure and using safe substitutes when available are the best ways to protect individual and public health.

[a]Gee D. Late lessons from early warnings: toward realism and precaution with endocrine-disrupting substances. *Environ Health Perspect.* 2006; 114(suppl 1):152–160.

Straightforward examples of interventions include recommending integrated pest management for homes and child care settings to avoid toxic pesticide exposures, and designating homes and child care settings as "tobacco-free zones" to prevent exposure to secondhand tobacco smoke (SHS). A more complex example is recommending that children with asthma avoid late afternoon exposure to outdoor air when ozone levels are elevated; for young athletes who have sports practice after school, it may be difficult to follow medical advice to stay indoors in air-conditioned spaces on ozone alert days.

When scientific information about other hazards is not complete, caution and common-sense avoidance of exposure should be advised (see Box 19-5). If an exposure is unnecessary and potentially harmful, it should be eliminated. Simply raising questions with parents often results in behavior changes that improve a child's environment.

Environmental History

While taking an environmental history may seem like a time-consuming endeavor for busy physicians, it is indeed part of a complete pediatric history. Most environmental hazards can be discovered by asking about social and occupational factors, including questions about where children spend time. Practices can integrate environmental questions into new patient questionnaires and review positive responses, similar to other reviews already taking place. For well-child visits, factors such as interval history, age of the child, season, and known hazards in the community can determine which hazards to ask about. Questions may be incorporated into electronic medical records, or be part of paper or electronic checklists for anticipatory guidance often used by pediatric practices. Key questions such as tobacco use in the home can be incorporated into "vital signs." Medical assistants and nurses can take much of this initial history and give age-appropriate anticipatory guidance, leaving the physician to handle complex issues. Incorporating environmental histories should become as routine as dietary, immunization, and developmental histories taken at well visits.

A targeted environmental history should be incorporated into sick visits. For example, tobacco use should be reviewed when a child has asthma, otitis media, or respiratory symptoms. This represents a therapeutic opportunity to reduce exposure and speed up return to health, and also a "teachable moment" about the effect of the physical environment on health. Interventions at the time of illness can include brief counseling about smoking cessation if family members smoke, and referral to quit-smoking resources. Because many illnesses have an environmental component, any acute, chronic, or recurrent illness should trigger a discussion of potential environmental contributors to onset, severity, and duration.

Diagnosis and Treatment of Environmental Illness

Depending on the complaint, the environmental contributors to illness may be more or less obvious and more or less amenable to intervention.

Especially difficult is a situation in which a parent suspects that an environmental chemical has caused a chronic disease and requests laboratory tests to document specific exposures. Because our knowledge of the health consequences of many exposures is incomplete or even absent, it can be frustrating for parents and physicians to have such discussions. In addition, laboratory testing is almost never indicated. As with all other situations in medicine, tests should *not* be ordered unless the outcome will change management. If laboratory tests are ordered, it is imperative that the correct tests are performed on appropriate specimens, that tests are done by credible laboratories, and that well-established reference values are available. Since some exposures are far removed in time from the visit, testing may not be an option. In particular, large panels of tests run on random blood, urine, or hair specimens are useless. Consulting with environmental health specialists is often the most efficient way to address parental concerns. This strategy may avoid generating information of unknown value that may further confuse or alarm an already worried parent (see Box 19-6).

BOX 19-6 Seven Cardinal Rules of Risk Communication

1. Involve the patient and parent in identifying and solving the problem.
2. Have a communication plan and a clear message.
3. Listen to the patient and parent's story.
4. Be honest, open, and frank.
5. Work with credible sources.
6. Provide access to information.
7. Speak clearly and with compassion.

Adapted from American Academy of Pediatrics Committee on Environmental Health. Risk assessment, risk management, and risk communication. In: Etzel RA, Balk SJ, eds. *Pediatric Environmental Health*. 3rd ed. Elk Grove Village, IL: American Academy of Pediatrics; 2012:847–858.

EXPANDED ROLES FOR PRIMARY CARE PHYSICIANS

Primary care physicians can improve PEH through direct patient care, by running our offices in environmentally conscious ways, and by influencing the larger community. In addition to taking environmental histories and incorporating environmental health anticipatory guidance into practice, we can begin to write "prescriptions" for environmental health interventions (see Tools for Practice). Each practice can develop a list of "top 10 ways" to encourage healthy environments for children and to protect them from relevant environmental hazards (Box 19-7). We can find opportunities to counsel children and families on larger issues, such as the importance to health of spending time in natural environments and the effect of climate change. Discussions may be framed in the context of "win–win" behaviors that improve health and the environment simultaneously. For example, choosing walking over travel in motor vehicles reduces greenhouse gas emissions, cleans the air, and increases physical activity. We can actively "green" offices in visible and educational ways such as switching to low-energy lighting, improving energy efficiency, using nontoxic cleaners, reducing use of disposable items, and supporting carpooling or bus transport. Finally, we can work in our communities for environmental changes that improve and sustain children's health. Local projects could include developing organic community gardens, organizing walking school buses to promote physical activity, or renovating old housing to eliminate lead paint, mold, and other hazards. In addition, physicians have a powerful political voice that can be used to educate and advocate with elected officials and rule makers to improve child health. This voice should be used wisely and often on behalf of current and future generations.

BOX 19-7 Example of a "Top 10 Ways to Promote Healthy Environments for Children"

1. Serve a variety of fresh fruits and vegetables, 5 to 9 portions daily; choose local, organic, and in-season foods when possible.
2. Encourage vigorous, daily outdoor play, in natural environments if possible; abide by heat advisories, air quality reports, and pollen counts for sensitive individuals.
3. Encourage tap water as the default beverage instead of juice or soda; test well water, use stainless steel drink containers, and filter tap water if there are questions about possible contaminants.
4. Make your child's environment(s) tobacco free—do not smoke or allow smoking around your child, including in motor vehicles. If you are a smoker, quit.
5. Use nonchemical pest control and integrated pest management; do not use chemical pesticides unless pests are dangerous and other alternatives are not available or are ineffective.
6. Be sun safe; avoid prolonged direct exposures during peak sun hours, seek shade, use protective clothing, apply sunscreen, wear sunglasses, and do not allow your teenager to tan in a tanning salon.
7. Microwave and store food in glass containers; never microwave in plastic.
8. Use simple, nontoxic cleaning supplies; avoid aerosols and air fresheners.
9. Have your home and child care setting/school tested for known hazards, such as lead and radon; remediate appropriately.
10. Model sustainable living; teach your child that "enough is plenty."

Each practice may develop its own Top 10 list depending on the local environment. For example, a practice in an inner city neighborhood with old housing stock, heavy traffic, and excessive noise might emphasize lead paint, use of public transport, and advocacy on noise abatement, whereas a suburban neighborhood in the sun belt might emphasize sun safety, attention to ozone alerts, and bike safety. Regardless, the emphasis should be on positive behaviors that are preventive in nature.

ENVIRONMENTAL HEALTH CHALLENGES

Despite major advances made in PEH over the past 2 to 3 decades, much remains unknown about environmental exposures and toxicities. The sheer number of manmade chemicals, for example, makes it impossible to study comprehensively the health consequences of exposure to all individual chemicals or to mixtures and their breakdown products. Interactions among multiple classes of environmental hazards, nutrition, social circumstances, and genetic makeup have effects on major childhood and adult epidemics. It is difficult to explore these interactions for individuals and populations. Exponential population growth, resource depletion, loss of biodiversity, and climate change pose major health challenges to future generations. Researchers and policy makers who grapple with

these large issues require input from professionals who care for children. Physicians who are knowledgeable about the effects of the environment on children's health can be valuable resources for improving the health of individual children and for helping to design a future that sustains health and the environment for future generations.

TOOLS FOR PRACTICE

Engaging Patient and Family

- *Rx for Prevention Prescription Slips (English)* (handouts), Physicians for Social Responsibility (www.psr.org/assets/pdfs/toolkit-rxpads-4up.pdf)
- *Rx for Prevention Prescription Slips (Spanish)* (handouts), Physicians for Social Responsibility (www.psr.org/assets/pdfs/toolkit-rxpadspan-4up.pdf)

Medical Decision Support

- *American Academy of Pediatrics Council on Environmental Health* (Web site) (www.aap.org/en-us/about-the-aap/Committees-Councils-Sections/Council-on-Environmental-Health)
- *Case Studies in Environmental Medicine* (continuing education), Agency for Toxic Substances and Disease Registry, Centers for Disease Control and Prevention (www.atsdr.cdc.gov/csem/csem.html)
- *Children's Environmental Health* (Web site), World Health Organization (www.who.int/ceh/en)
- *National Center for Environmental Health* (Web site), Centers for Disease Control and Prevention (www.cdc.gov/nceh)
- *Protecting Children's Environmental Health* (Web site), US Environmental Protection Agency (www2.epa.gov/children)
- *Pediatric Environmental Health Specialty Units* (Web page), (www.pehsu.net)

Practice Management and Care Coordination

- *Pediatric Environmental Health Toolkit* (toolkit), Physicians for Social Responsibility (www.psr.org/resources/pediatric-toolkit.html)

SUGGESTED READINGS

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Chapter 20

IMMUNIZATIONS

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INTRODUCTION

Vaccine-preventable diseases have left a legacy of suffering that must not be forgotten. Although considerable progress has been marked in recent years, children in the United States and many children elsewhere die when they lose their very personal battles with vaccine-preventable diseases.

Vaccination was one of the most important achievements in public health in the 20th century. The most salient feature of this achievement is decreased disease levels. Compared with pre vaccination era disease levels, the current US disease levels are 92% to 100% lower. Recent immunization successes include the first-ever interruption of indigenous measles and rubella transmission in the United States and the interruption of wild-type polio transmission in the Western hemisphere. Routine childhood vaccination is one of the few health care interventions that saves both lives and dollars: compared with a no-vaccination program, routine vaccination saves from $2 (for hepatitis B vaccination) to $29 (for measles-mumps-rubella [MMR] vaccination) for every dollar spent.

The primary reason for the low vaccine-preventable disease incidence is high immunization coverage levels, an achievement by the health care system that was accomplished during a period of increasing complexity in the immunization schedule. These successes resulted largely from major efforts by private and public health care providers. Sustaining success will require even greater effort, because the process of vaccinating children and adolescents is becoming increasingly complicated as the number of vaccines and vaccine combination choices increases.

The current US recommended childhood and adolescent immunization schedule is updated annually; the most current version is available on the Centers for Disease Control and Prevention (CDC) Web site.

PRINCIPLES OF VACCINATION

Live versus Inactivated Vaccines

Currently available vaccines are either live, which replicate in the body, or inactivated. Live injected vaccines usually induce immunity through a single dose and, unlike inactivated vaccines, are susceptible to vaccine failure caused by circulating antibodies, including residual maternal antibodies in infants. Live vaccines include:

- Those that protect against viruses (eg, MMR, varicella, rotavirus, live attenuated influenza intranasal vaccine [LAIV], yellow fever, vaccinia, oral polio vaccine [OPV])

- Those that protect against bacteria (eg, Bacillus Calmette–Guérin, oral typhoid vaccine)

Inactivated vaccines do not contain infectious particles that can replicate in the body; they generally require several doses to immunize patients completely. Inactivated vaccines include:

- Inactivated viruses (eg, inactivated polio vaccine [IPV], hepatitis A, rabies)
- Inactivated subunits (eg, acellular pertussis, hepatitis B, human papillomavirus [HPV], split virus influenza, typhoid Vi)
- Toxoid (diphtheria, tetanus) agents
- Polysaccharides—either unconjugated (pneumococcal, meningococcal) or conjugated (*Haemophilus influenzae* type b [Hib], pneumococcal, meningococcal)

Spacing and Timing

Routine Schedule

The routine vaccination schedules are harmonized among the American Academy of Pediatrics (AAP), the American Academy of Family Physicians (AAFP), and the CDC Advisory Committee on Immunization Practices (ACIP). The harmonized schedules are not simple, but they do allow for office preferences by indicating acceptable ranges for routine on-time vaccination scheduling. The ranges were created so that offices might more easily accommodate routine vaccination into their well-child care schedule. To ensure timely immunizations, vaccinating early within the acceptable age range is important. The current version of the vaccination schedules can be found on the CDC Web site (www.cdc.gov/vaccines/schedules/hcp/child-adolescent.html).

Intervals Between Different Vaccines Not Administered Simultaneously

Using all routine vaccines simultaneously is safe and effective, provided that vaccines are not combined within a single syringe (with the exception of combination vaccines). No contraindications exist to giving any 2 or more different routine childhood vaccines at the same visit.

Vaccines that are not administered simultaneously may be given without regard to intervals, with the exception that live vaccines not given by the oral route (eg, MMR, varicella, LAIV) that are not administered simultaneously should be separated by at least 4 weeks. This *4-week separation rule* is intended to reduce the theoretical risk of interference from the first vaccine on the subsequent vaccine. If, for example, varicella vaccine is given only 1 week after MMR, then the varicella vaccine should be repeated or serologic testing should be used to confirm seroconversion.

Physicians, parents, and, no doubt, children prefer fewer injections. As a consequence of the increasing number of diseases that can be prevented through vaccination, the number of required injections is continually increasing. The number of combination vaccines available has also increased. Combination vaccines reduce the number of injections and are preferred, when available, by ACIP, the AAFP, and the AAP. All vaccines for which the child is eligible should be offered whenever possible. This strategy not only keeps the child on schedule, but also prevents an additional, unnecessary office visit.

Minimal Age and Intervals Between Different Doses of a Multidose Vaccine

Vaccine doses that are given too early in life or too soon after a previous dose may be less effective. Table 20-1 shows the earliest acceptable ages for administration of the routinely recommended childhood vaccines and the minimal spacing between their doses. The most current version of this table can be found at www.cdc.gov/vaccines/pubs/pinkbook.

Physicians often ask whether to count a vaccine dose given at an interval shorter than the minimal interval. For example, should a child who received doses 3 and 4 of diphtheria-tetanus-acellular pertussis (DTaP) vaccines within less than 6 months be revaccinated? Was the dose valid if a child received an MMR vaccination before 12 months of age? Though state requirements for school entry vary, ACIP considers a vaccination valid if the vaccine dose was within 4 days of the minimal interval. Vaccine doses, of course, are considered invalid if an incorrectly small amount was used, and there may be a higher risk of side effects if an incorrectly large amount was used. Steps should be taken to prevent these errors from occurring, and the physician should remember that vaccination is a safe procedure, even if the child is given more than the recommended number of doses. Overvaccination (ie, vaccination with more doses than recommended) with live vaccines does not have adverse biologic consequences because the extra vaccine virus will not infect an already immune person. Overvaccination with inactivated vaccines might cause an increase in local reactions if antibody levels are high.

Prolonged intervals between doses of a multidose vaccination series do not diminish vaccine effectiveness, although the benefit of vaccination may be delayed by prolonged intervals. Series never need to be restarted because of prolonged intervals (with the exception of the oral typhoid vaccine).

Late-Start or Interrupted Schedule

Some children start routine vaccination late. The recommended compressed, catch-up, or accelerated immunization schedule for such children is derived from the minimal intervals for the routine vaccinations. A catch-up schedule is published annually with the routine schedule.

The presentation of a new patient whose vaccination status is unknown presents a challenge. In this situation, the physician must determine if any immunization record exists for the child and, if so, must obtain a copy of the record or a report from the previous physician. If no record can be found, then the child should be presumed to be unvaccinated, and the vaccination series should be given using the accelerated schedule. Serologic testing can be considered for some antigens (eg, MMR, hepatitis B).

Table 20-1 Recommended and Minimum Ages and Intervals Between Doses of Routinely Recommended Vaccines[a,b,c,d]

VACCINE AND DOSE NUMBER	RECOMMENDED AGE FOR THIS DOSE	MINIMUM AGE FOR THIS DOSE	RECOMMENDED INTERVAL TO NEXT DOSE	MINIMUM INTERVAL TO NEXT DOSE
Diphtheria-tetanus-acellular pertussis (DTaP)-1[e]	2 months	6 weeks	8 weeks	4 weeks
DTaP-2	4 months	10 weeks	8 weeks	4 weeks
DTaP-3	6 months	14 weeks	6–12 months	6 months[f]
DTaP-4	15–18 months	15 months[g]	3 years	6 months
DTaP-5	4–6 years	4 years	—	—
Haemophilus influenzae type b (Hib)-1[f, h]	2 months	6 weeks	8 weeks	4 weeks
Hib-2	4 months	10 weeks	8 weeks	4 weeks
Hib-3[i]	6 months	14 weeks	6–9 months	8 weeks
Hib-4	12–15 months	12 months	—	—
Hepatitis A (HepA)-1	12–23 months	12 months	6–18 months	6 months
HepA-2	≥18 months	18 months	—	—
Hepatitis B (HepB)-1[e]	Birth	Birth	4 weeks–4 months	4 weeks
HepB-2	1–2 months	4 weeks	8 weeks–17 months	8 weeks
HepB-3[j]	6–18 months	24 weeks	—	—
Herpes zoster (HZV)[k]	≥60 years	60 years	—	—
Human papillomavirus (HPV)-1[l]	11–12 years	9 years	8 weeks	4 weeks
HPV-2	11–12 years (+ 2 months)	9 years (+ 4 weeks)	4 months	12 weeks[m]
HPV-3[m]	11–12 years (+ 6 months)	9 years (+24 weeks)	—	—
Influenza, inactivated (IIV)[n]	≥6 months	6 months[o]	4 weeks	4 weeks
Influenza, live attenuated (LAIV)[n]	2–49 years	2 years	4 weeks	4 weeks
Measles-mumps-rubella (MMR)-1[p]	12–15 months	12 months	3–5 years	4 weeks
MMR-2[p]	4–6 years	13 months	—	—
Meningococcal conjugate (MCV)-1[q]	11–12 years	6 weeks[r]	4–5 years	8 weeks
MCV-2	16 years	11 years (+ 8 weeks)	—	—
Meningococcal polysaccharide (MPSV4)-1[q]	—	2 years	5 years	5 years
MPSV4-2	—	7 years	—	—
Pneumococcal conjugate (PCV)-1[h]	2 months	6 weeks	8 weeks	4 weeks
PCV-2	4 months	10 weeks	8 weeks	4 weeks
PCV-3	6 months	14 weeks	6 months	8 weeks
PCV-4	12–15 months	12 months	—	—
Pneumococcal polysaccharide (PPSV)-1	—	2 years	5 years	5 years
PPSV-2[s]	—	7 years	—	—
Poliovirus, Inactivated (IPV)-1[e]	2 months	6 weeks	8 weeks	4 weeks
IPV-2	4 months	10 weeks	8 weeks–14 months	4 weeks
IPV-3	6–18 months	14 weeks	3–5 years	6 months
IPV-4[t]	4–6 years	4 years	—	—
Rotavirus (RV)-1[u]	2 months	6 weeks	8 weeks	4 weeks
RV-2	4 months	10 weeks	8 weeks	4 weeks
RV-3[v]	6 months	14 weeks	—	—
Tetanus-diphtheria (Td)	11–12 years	7 years	10 years	5 years

Table 20-1 Recommended and Minimum Ages and Intervals Between Doses of Routinely Recommended Vaccines[a,b,c,d]—cont'd

VACCINE AND DOSE NUMBER	RECOMMENDED AGE FOR THIS DOSE	MINIMUM AGE FOR THIS DOSE	RECOMMENDED INTERVAL TO NEXT DOSE	MINIMUM INTERVAL TO NEXT DOSE
Tetanus-diphtheria-acellular pertussis (Tdap)[w]	≥11 years	7 years	—	—
Varicella (Var)-1[p]	12–15 months	12 months	3–5 years	12 weeks[x]
Var-2[p]	4-6 years	15 months[y]	—	—

[a]Combination vaccines are available. Use of licensed combination vaccines is generally preferred to separate injections of their equivalent component vaccines. When administering combination vaccines, the minimum age for administration is the oldest age for any of the individual components (*exception:* the minimum age for the first dose of MenHibrix is 6 weeks); the minimum interval between doses is equal to the greatest interval of any of the individual components.
[b]Information on travel vaccines including typhoid, Japanese encephalitis, and yellow fever, is available at www.cdc.gov/travel. Information on other vaccines that are licensed in the United States but not distributed, including anthrax and smallpox, is available at www.bt.cdc.gov.
[c]Ages and intervals less than 4 months may be expressed in weeks. When the term "months" is used to express an age or interval, it means calendar months.
[d]A dash used to express a range (as in "12–15 months") means "through."
[e]Combination vaccines containing a hepatitis B component (Comvax, Pediarix, and Twinrix) are available. These vaccines should not be administered to infants younger than 6 weeks because of the other components (ie, Hib, DTaP, HepA, and IPV).
[f]A special grace period of 3 months, based on expert opinion, can be applied to the minimum age of 15 months when evaluating records retrospectively, which will result in an acceptable minimum age of 12 months. An additional 4 days should not be added to this grace period.
[g]The minimum recommended interval between DTaP-3 and DTaP-4 is 6 months. However, DTaP-4 need not be repeated if administered at least 4 months after DTaP-3. This is a special grace period (2 months long) that can be used while evaluating records retrospectively. An additional 4 days should not be added to this grace period.
[h]Children receiving the first dose of Hib or pneumococcal conjugate vaccine at age 7 months or older require fewer doses to complete the series.
[i]If PRP-OMP (Pedvax-Hib) was administered at ages 2 and 4 months, a dose at age 6 months is not required.
[j]HepB-3 should be administered at least 8 weeks after HepB-2 and at least 16 weeks after HepB-1, and should not be administered before age 24 weeks.
[k]Herpes zoster vaccine is recommended as a single dose for persons 60 years of age and older.
[l]Bivalent HPV vaccine (Cervarix) is approved for females 9 through 25 years of age. Quadrivalent HPV vaccine (Gardasil) is approved for males and females 9 through 26 years of age.
[m]The minimum age for HPV-3 is based on the baseline minimum age for the first dose (9 years) and the minimum interval of 24 weeks between the first and third doses. Dose 3 need not be repeated if it is given at least 16 weeks after the first dose (and if the intervals between doses 1 and 2 and doses 2 and 3 are maintained at 4 weeks and 12 weeks, respectively).
[n]One dose of influenza vaccine per season is recommended for most people. Children younger than 9 years of age who are receiving influenza vaccine for the first time should receive 2 doses this season. See current influenza recommendations for other factors affecting the decision to administer 1 vs 2 doses to children younger than 9 years.
[o]The minimum age for inactivated influenza vaccine varies by vaccine manufacturer and formulation. See package inserts for vaccine-specific minimum ages.
[p]Combination measles-mumps-rubella-varicella (MMRV) vaccine can be used for children aged 12 months through 12 years. (See CDC. General recommendations on immunization: recommendations of the ACIP. *MMWR* 2011;60[No. RR-2],7.)
[q]Revaccination with meningococcal vaccine is recommended for previously vaccinated persons who remain at high risk for meningococcal disease. (See CDC. Updated recommendations from the ACIP for vaccination of persons at prolonged increased risk for meningococcal disease. *MMWR* 2009;58:[1042-3])
[r]Menactra can be given as young as 9 months for high-risk children. Menveo can be given as young as 2 months for high-risk children. MenHibrix can be given as young as 6 weeks for high-risk children. MenHibrix is given as a 4-dose series at 2 months, 4 months, 6 months, and 12–18 months.
[s]A second dose of PPSV 5 years after the first dose is recommended for persons <65 years of age at highest risk for serious pneumococcal infection, and for those who are likely to have a rapid decline in pneumococcal antibody concentration. (See CDC. Prevention of pneumococcal disease: recommendations of the ACIP. *MMWR* 1997;46[No. RR-8].)
[t]A fourth dose is not needed if the third dose was administered on or after the 4th birthday and at least 6 months after the previous dose.
[u]The first dose of rotavirus must be administered between 6 weeks 0 days and 14 weeks 6 days. The vaccine series should not be started after age 15 weeks 0 days. Rotavirus vaccine should not be administered to children older than 8 months 0 days, regardless of the number of doses received before that age.
[v]If 2 doses of Rotarix are administered as age appropriate, a third dose is not necessary.
[w]Only 1 dose of Tdap is recommended. Subsequent doses should be given as Td. For management of a tetanus-prone wound in a person who has received a primary series of a tetanus-toxoid containing vaccine, the minimum interval after a previous dose of any tetanus-containing vaccine is 5 years.
[x]For persons beginning the series on or after the 13th birthday, the minimum interval from varicella-1 to varicella-2 is 4 weeks. While it is not recommended if a child younger than 13 years receives varicella-2 at an interval of 4 weeks or longer from varicella-1, the dose does not need to be repeated.
[y]A special grace period of 2 months, based on expert opinion, can be applied to the minimum age of 15 months when evaluating records retrospectively, which will result in an acceptable minimum age of 13 months. An additional 4 days should not be added to this grace period.

Intervals Between Live Injected Vaccines and Antibody-Containing Blood Products

Live injected vaccines (eg, MMR and varicella vaccines) have to replicate in the body to induce immunity and may be compromised by circulating antibodies against the vaccine virus. Live vaccines not administered by injection (eg, LAIV, oral typhoid, OPV) are thought to be unaffected by circulating antibodies. Generally, inactivated vaccines are not significantly affected by circulating antibodies and can be administered without regard to the relative timing of the administration of immune globulin–containing products.

MMR and varicella vaccine doses given more than 14 days before immune globulin–containing products are administered have time to replicate and are effective. When live injected vaccines are given after antibody-containing blood products, the situation is more complex. The specific immune globulin–containing product and its dose dictate the waiting period necessary before a valid dose of a live injected vaccine is given. MMR and varicella vaccination should be delayed from 3 months to 11 months, depending on the specific immune globulin preparation administered. Details of the appropriate waiting period can be found in the AAP *Red Book* and on the CDC Web site.

Vaccinations Administered in Foreign Countries

Determining the immunization status of foreign-born children or other children who have been partially or completely vaccinated in another country can be difficult. Vaccines, their abbreviations, and vaccination age criteria often differ among countries. The immunization status needs to be determined for all children and special attention paid to the rest of the family in the case of recent immigration.

The first assumption to make is that the vaccines administered in other countries were as potent as those available in the United States. Then, it becomes a matter of determining which vaccines were administered and whether the doses qualify as valid doses when considering the minimal ages of administration and the minimal intervals between doses. Determining which vaccines were administered can be difficult because the standard abbreviations recorded in handheld vaccination records may be different from those used in the United States. Translation of foreign-language terms can be facilitated with materials from the CDC. Assistance with specific questions can be obtained from state immunization programs or from the CDC National Center for Immunization and Respiratory Diseases (www.cdc.gov/vaccines/pubs/pinkbook/downloads/appendices/B/foreign-products-tables.pdf) or via telephone (800-CDC-INFO, ie, 800-232-4636) or e-mail (nipinfo@cdc.gov). Once the vaccine types are determined, the CDC schedule for catch-up immunizations can be used to determine which doses are valid and which, if any, need to be repeated. The most current version of this table can be found at www.cdc.gov/vaccines/schedules. As with vaccines administered in the United States, the CDC recommends that vaccine doses given 4 or fewer days before the minimum interval be counted as valid (except the rabies vaccine), unless state or local requirements specify otherwise.

Variation in vaccination strategies creates a problem for physicians caring for internationally adopted children and recent immigrants. Although evidence suggests that the documented vaccination status of foreign adopted children is not always accurate, the CDC's Advisory Committee on Immunization Practices (ACIP) recommends when interpreting the vaccination status of international adoptees is that documented vaccinations (that include the doses and dates of administration) are acceptable proof of vaccination.

Contraindications and Precautions

The reader is encouraged to visit the *General Recommendations* and the CDC's detailed *Recommendations and Guidelines: Vaccine Contraindications and Precautions* (www.cdc.gov/vaccines/recs/vac-admin/contraindications.htm). Contraindications and precautions are also outlined in the invaluable table, *Summary of Recommendations for Child/Teen Immunization*, which is available at www.immunize.org/catg.d/p2010.pdf.

Anaphylactic Allergy

Anaphylactic-type allergy to a vaccine or a vaccine component, which includes even mild urticarial reactions, is a contraindication to further vaccination with the vaccine in question unless the recipient has been desensitized.

Encephalopathy

Encephalopathy within 7 days after a previous dose of a pertussis-containing vaccine (eg, DTaP, tetanus-diphtheria-acellular pertussis [TdaP]), not attributable to another identifiable cause, is a contraindication to further vaccination with pertussis-containing vaccines.

Minor, Acute Illnesses

Some children will be ill at the time of a well-child visit or will be in need of a vaccination at an illness visit. In these situations, the pediatrician must decide whether to recommend vaccination based on 2 questions: Will vaccination be safe for this ill child? And, if not vaccinated at this visit, will the child be brought back for vaccination?

Minor illnesses, including upper respiratory tract infections, otitis media, and diarrheal illnesses, whether the individual is febrile or not, are not valid contraindications to vaccination. A second, perhaps more difficult, consideration is whether minor vaccine side effects, such as fever, will cause diagnostic confusion during the follow-up period for the illness—a problem that may be especially difficult when caring for very young infants.

Pediatricians often struggle to determine the likelihood that any given child will return for a scheduled vaccination visit. Although past appointment-keeping behavior will help in the judgment, it is not completely reliable. Because vaccinating children who have minor illnesses is safe and effective, and because it may be unclear whether a child will be brought back for an appointment, vaccinating the ill child is best, especially if he or she has missed previous preventive care visits.

Persons with moderate or severe acute illness should be vaccinated as soon as the acute illness has improved.

Immunocompromise

There are many possibilities regarding vaccinations for persons with immunocompromising conditions. For example, persons with altered immunocompetence might be at increased risk for an adverse reaction after administration of live, attenuated vaccines because of uninhibited replication, so these vaccines may need to be deferred until immune function has improved; these patients may need to be revaccinated with inactivated vaccines after immune function has improved if vaccination during the period of altered immunocompetence was less effective; or these patients may need certain vaccines (eg, inactivated influenza and pneumococcal vaccines) because of specific disease vulnerabilities. Because of the variety of immunocompromising conditions and their degree of severity, as well as the variety of vaccine-preventable diseases, vaccination of immunocompromised children often is best managed in consultation with a pediatric infectious disease specialist.

WHO IS IMMUNOCOMPROMISED? Children who have congenital immunodeficiency, leukemia, lymphoma, or generalized malignancy should not receive live vaccines. Persons receiving immunosuppressive

treatments (eg, alkylating agents, antimetabolites, and radiation therapy) also should not receive live vaccines. Persons receiving daily large doses of corticosteroids (the equivalent of 2 mg/kg of prednisone per day) for 14 days or longer should not receive live virus vaccines; live vaccines should be deferred for at least 30 days after treatment cessation or dose reduction. Live vaccine use is not contraindicated if the corticosteroid is aerosolized (as in asthma inhalers) or topical, nor if it is given on an alternate-day short course (<14 days), or if the child is on a physiologic replacement schedule.

LIVE VACCINES. In general, live vaccines cannot be used in immunocompromised individuals because of the potential for severe or fatal reactions from uncontrolled replication of the vaccinating agent. Exceptions to this rule include the following:

- HIV infection: Limited data among human immunodeficiency virus (HIV)–infected children (specifically CDC class N, A, or B with age-specific $CD4^+$ T-lymphocyte percentages of ≥15%) indicate that varicella vaccine is immunogenic, effective, and safe. When indicated, the ACIP recommends MMR vaccination for all asymptomatic and mildly symptomatic HIV-infected persons who do not have evidence of severe immunosuppression. The MMR with varicella (MMRV) vaccine should not be administered to persons with HIV infection.
- Immunocompromised people with limited humoral immunodeficiency (eg, hypogammaglobulinemia, immunoglobulin A deficiency) may be routinely vaccinated with varicella vaccine.
- Healthy persons with anatomic or functional asplenia can receive intranasal influenza vaccine (LAIV).
- Children with deficiencies in complement or with asplenia can receive both live, attenuated viral and bacterial vaccines.
- Children with defects in phagocyte function (eg, chronic granulomatous disease or myeloperoxidase deficiency) can receive live, attenuated viral—but not bacterial—vaccines.
- Immunocompromise is a precaution but not a contraindication to the live, oral pentavalent rotavirus vaccine.

INACTIVATED VACCINES. Persons with altered immunocompetence generally are advised to receive injectable influenza vaccine and age-appropriate polysaccharide-based vaccines (PCV, PPSV, MCV4, MPSV4, and Hib) on the basis of demonstrated effectiveness or an increased risk for disease if the vaccine is withheld. However, during chemotherapy or radiation therapy, vaccination should be avoided if possible (except with inactivated influenza vaccine) because antibody responses might be suboptimal. Patients vaccinated within 14 days before starting immunosuppressive therapy or while receiving immunosuppressive therapy should be considered unimmunized and should be revaccinated at least 3 months after therapy is discontinued if immune competence has been restored.

BONE MARROW TRANSPLANT. For vaccination of bone marrow transplant recipients, the physician should consult the *Red Book* or the *General Recommendations*.

HOUSEHOLD CONTACTS. Household and other close contacts of persons with altered immunocompetence should be vaccinated as indicated; in particular, they should receive annual influenza vaccination (intranasal or injectable). MMR and varicella vaccines—which are live vaccines contraindicated for use in most immunocompromised people—should be given to susceptible contacts of immunocompromised people. If the varicella vaccine recipient has a rash after vaccination, direct contact with susceptible household contacts should be avoided until the rash resolves. OPV, which is used outside the United States, should not be given to people who are immunocompromised or to their close contacts. Of course, all members of the household should wash their hands after changing the diaper of an infant, in particular to minimize rotavirus transmission.

Pregnancy

Guidelines on vaccination of pregnant women can be found in the *General Recommendations* and on the CDC Web site. The following briefly summarizes key points on routine vaccines (but not travel vaccines).

LIVE VACCINES. Because of the theoretical risk to the fetus, women known to be pregnant generally should not receive live, attenuated virus vaccines (eg, MMR, varicella, intranasal influenza) or live bacterial vaccines. However, potential risks of vaccinating pregnant women are usually outweighed by the benefits when the likelihood of disease exposure is high, infection would pose a risk to the mother or fetus, and the vaccine is unlikely to cause harm. Routine pregnancy testing of women of childbearing age before administering a live-virus vaccine is not recommended. Women should avoid pregnancy for 4 weeks after vaccination with MMR, MMRV, or varicella vaccines. If a pregnant woman is inadvertently vaccinated or becomes pregnant within 4 weeks after receiving these vaccines, she should be counseled about the theoretical basis of concern for the fetus; however, MMR or varicella vaccination during pregnancy should not be considered a reason to terminate the pregnancy.

INACTIVATED VACCINES. Pregnant women generally may receive inactivated vaccines and toxoids. Routine influenza vaccination is recommended for all women who are or will be in any trimester of pregnancy during influenza season—usually early October through late March in the United States. The adult tetanus-diphtheria-acellular pertussis (Tdap) should be given to pregnant women during each pregnancy, preferably between 27 and 36 weeks' gestation, regardless of prior vaccination with the tetanus-diphtheria (Td) or Tdap. The CDC recommends that hepatitis B vaccine should be given to a pregnant woman for whom it is indicated. Vaccines against hepatitis A and meningococcal disease should be considered for women at increased risk for those infections. Similarly, IPV can be administered to pregnant women at risk for exposure to wild-type poliovirus infection. HPV vaccines are not recommended for use in pregnant women.

Prematurity

Preterm infants should be vaccinated using the routine schedule based on their chronologic age (ie, time

since birth, regardless of gestational age or birth weight) and the standard doses of vaccine, with 2 exceptions:

HEPATITIS B VACCINE. Preterm infants born to mothers who are hepatitis B surface antigen (HBsAg)-positive or with unknown HBsAg status must receive hepatitis B vaccine within 12 hours after birth; then 3 additional doses of hepatitis B vaccine should be administered, beginning when the infant is 1 month of age. The infant also must be given hepatitis B immune globulin within 12 hours of birth unless postnatal serology shows the mother to be HBsAg-negative. Infants weighing less than 2,000 g born to HBsAg-negative mothers should receive the first dose of the hepatitis B series at chronologic age 1 month or at hospital discharge.

ROTAVIRUS VACCINE. If a child of at least 6 weeks of age has been hospitalized since birth, deferral of rotavirus vaccine is recommended until discharge. The rotavirus vaccine series should not be initiated for infants 15 weeks or older.

Vaccine Safety

Vaccine safety concerns have been borne out in studies (eg, RotaShield and intussusception), a biologically plausible but unsubstantiated association (eg, thimerosal in the birth dose of hepatitis B vaccine and autism), or speculation (MMR vaccine and autism). New concerns are likely to arise. A few reliable, regularly updated sources of vaccine safety information include:

- American Academy of Pediatrics (www.healthychildren.org/English/safety-prevention/immunizations/Pages/How-Safe-are-Vaccines.aspx)
- Centers for Disease Control and Prevention (www.cdc.gov/vaccinesafety/index.html)
- Immunization Action Coalition (www.immunize.org/safety)
- Vaccine Education Center (www.chop.edu/service/vaccine-education-center/vaccine-safety)
- Vaccine Safety Institute (www.vaccinesafety.edu)

GREAT EXPECTATIONS FOR THE FUTURE OF VACCINATION

Until the late 1980s, routine childhood vaccination had been a field marked by slow but steady progress. Since then, routine vaccination has been anything but routine. Driven by major advances in biotechnology, the performance of childhood immunization, in terms of disease prevention, has been remarkable. However, this increased performance has come at the cost of increased complexity, including more choices among vaccines and combinations of vaccines and a more complex and rapidly changing immunization schedule. For example, combination vaccines allow prevention of diseases with fewer injections; however, the presence of nonoverlapping, noncomplementary vaccines (eg, DTaP–Haemophilus influenzae type B [Hib], Hib-HBV) makes the choice of which vaccines to purchase difficult.

Advances in biotechnology will continue to bring new combination vaccines, vaccines against additional diseases, improvements in existing vaccines, and more changes in the routine vaccination schedule. At this time, more than 20 vaccines are at various stages of development and testing. More combination vaccines will lead to greater complexity in the short term, but these combinations will eventually provide protection from disease with fewer injections; they will also facilitate vaccination against newly preventable diseases by "piggybacking" new vaccines onto accepted and fully implemented vaccines.

Just as vaccine technology is changing, so is the US immunization delivery system. For example, a greater proportion of immunizations are now given in the primary care setting than a decade ago. Continued changes in immunization delivery will be driven by changes in the financing of vaccines, changes in the health care industry, and parental preferences.

Much has been accomplished since 1796 when Edward Jenner inoculated James Phipps with cowpox, terming the procedure *vaccination* (after the word *vacca* for cow). The future is bright for children to live free of many vaccine-preventable diseases. By combining technologic advances of vaccines with aggressive delivery of immunizations by primary care physicians and public health practitioners, the present health care system will ensure healthier lives for children.

TOOLS FOR PRACTICE

Engaging Patient and Family

Answers to Frequently Asked Questions

- *Ask the Expert: Combination Vaccines* (Web page), Immunization Action Coalition (www.immunize.org/askexperts/experts_combo.asp)
- *Basics and Common Questions: 10 Things You Need to Know About Immunizations* (fact sheet), Centers for Disease Control and Prevention (www.cdc.gov/vaccines/vac-gen/10-shouldknow.htm)
- *Parents' Guide to Childhood Immunization* (booklet), Centers for Disease Control and Prevention (www.cdc.gov/VACCINES/PUBS/parents-guide/default.htm)
- *Vaccinate Your Baby* (Web page), Every Child By Two (www.vaccinateyourbaby.org/faq/index.cfm)

Immunization Schedules

- *Catch-Up Scheduler for Children 6 Years and Younger* (Web site), Vacscheduler.org (www.vacscheduler.org)
- *Immunizations for Babies: A Schedule for Parents* (fact sheet), Immunization Action Coalition (www.immunize.org/catg.d/p4010.pdf)
- *Immunization Schedules* (Web page), American Academy of Pediatrics (www2.aap.org/immunization/IZSchedule.html)

Childhood and Adolescent Immunizations

- *A Look at Each Vaccine* (Web page), Vaccine Education Center of Children's Hospital of Philadelphia (www.chop.edu/service/vaccine-education-center/a-look-at-each-vaccine)
- *Books and Periodicals* (Web page), Immunization Action Coalition (www.immunize.org/resources/books_refer.asp)

- *Parent Handouts* (Web page), *Immunization Action Coalition (www.immunize.org/handouts/discussing-vaccines-parents.asp)*
- *Vaccinations for Preteens and Teens, Age 11–19 Years* (fact sheet), Immunization Action Coalition (www.immunize.org/catg.d/p4020.pdf)
- *Vaccine Preventable Diseases* (Web page), American Academy of Pediatrics (www.healthychildren.org/English/health-issues/vaccine-preventable-diseases/Pages/default.aspx)
- *What Vaccines Do You Need? Adolescent and Adult* (questionnaire), Centers for Disease Control and Prevention (www2.cdc.gov/nip/adultimmsched)

Vaccine Safety

- *Immunizations* (Web page), American Academy of Pediatrics (www.healthychildren.org/English/safety-prevention/immunizations/Pages/default.aspx)
- *Talking About Vaccines: Vaccine Safety* (Web page), Immunization Action Coalition (www.immunize.org/safety)
- *Vaccine Information Statements* (Web page), Immunization Action Coalition (www.immunize.org/vis)
- *Vaccine Safety* (Web page), American Academy of Pediatrics (www2.aap.org/immunization/families/safety.html)
- *Vaccine Safety* (Web page), Centers for Disease Control and Prevention (www.cdc.gov/vaccinesafety/index.html)
- *Vaccine Safety* (Web page), Vaccine Education Center of Children's Hospital of Philadelphia (www.chop.edu/service/vaccine-education-center/vaccine-safety/vaccine-safety.html)

Medical Decision Support

- *AAP Immunization Initiatives Newsletter*, American Academy of Pediatrics (www.aap.org/en-us/Documents/immunization_newsletter.pdf)
- *ACIP Vaccine Recommendations* (Web page), Centers for Disease Control and Prevention (www.cdc.gov/vaccines/hcp/acip-recs/index.html)
- *Basics and Common Questions: Some Common Misconceptions About Vaccination* (Web page), Centers for Disease Control and Prevention (www.cdc.gov/vaccines/pubs/parents-guide/parents-guide-part4.html)
- *Epidemiology and Prevention of Vaccine-Preventable Diseases (The Pink Book)* (e-book), Centers for Disease Control and Prevention (www.cdc.gov/vaccines/pubs/pinkbook/index.html)
- *Immunization Training Guide* (booklet), American Academy of Pediatrics (www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/immunization/Pages/training-guide.aspx)
- *List of Vaccines Used in United States* (Web page), Centers for Disease Control and Prevention (www.cdc.gov/vaccines/vpd-vac/vaccines-list.htm)
- *Red Book: 2015 Report of the Committee on Infectious Diseases*, 30th ed (book), American Academy of Pediatrics (shop.aap.org)
- *Reporting Adverse Events* (Web page), Centers for Disease Control and Prevention (www.cdc.gov/vaccines/programs/vfc/providers/reports.html)
- *Screening Checklist for Contraindications to Vaccines for Children and Teens* (screen), Centers for Disease Control and Prevention (www.immunize.org/catg.d/p4060scr.pdf)
- *Summary of Recommendations for Childhood and Adolescent Immunization* (chart), Immunization Action Coalition (www.immunize.org/catg.d/rules1.pdf)
- *Vaccine Storage and Handling* (Web page), Centers for Disease Control and Prevention (www.cdc.gov/VACCINES/RECS/storage/default.htm)
- *Yellow Book Homepage* (Web page), Centers for Disease Control and Prevention (wwwnc.cdc.gov/travel/page/yellowbook-home)

Practice Management and Care Coordination

- *Business Case for Pricing New Vaccines* (Web page), American Academy of Pediatrics (www.aap.org/en-us/professional-resources/practice-support/Pages/Practice-Support.aspx)
- *Clinic Resources* (Web page), Immunization Action Coalition (www.immunize.org/clinic)
- *Immunization* (Web page), American Academy of Pediatrics (www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/immunization/Pages/default.aspx)
- *Standing Orders for Administering Vaccines* (Web page), Immunization Action Coalition (www.immunize.org/standing-orders)
- *State Information* (Web page), Immunization Action Coalition (www.immunize.org/stateinfo)
- *Vaccine Coding* (Web page), American Academy of Pediatrics (www.aap.org/en-us/professional-resources/practice-support/Coding-at-the-AAP/Pages/Vaccine-Coding.aspx)

AAP POLICY

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American Academy of Pediatrics Committee on Infectious Diseases. Immunization for *Streptococcus pneumoniae* infections in high-risk children. *Pediatrics*. 2015;136(4):792–808 (pediatrics.aappublications.org/content/136/4/792)

American Academy of Pediatrics Committee on Infectious Diseases. Prevention of rotavirus disease: updated guidelines for use of rotavirus vaccine. *Pediatrics.* 2009;123(5):1412–1420 (pediatrics.aappublications.org/content/123/5/1412)

American Academy of Pediatrics Committee on Practice and Ambulatory Medicine and Council on Community Pediatrics. Increasing immunization coverage. *Pediatrics.* 2010;125(6):1295–1304 (pediatrics.aappublications.org/content/125/6/1295)

American Academy of Pediatrics Committee on Practice and Ambulatory Medicine. Immunization information systems. *Pediatrics.* 2006;118(3):1293–1295. Reaffirmed October 2011 (pediatrics.aappublications.org/content/118/3/1293)

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Community Health

Chapter 21

THE ESSENTIAL ROLE OF THE PRIMARY CARE PEDIATRICIAN

Francis E. Rushton, MD

Community pediatrics has been described as the intersection between what individual physicians do on behalf of children and the other surrounding factors and services that affect child health. In 1968, Robert J. Haggerty, MD, defined community pediatrics as "Taking responsibility for all children in a community, providing preventive and curative services, and understanding the determinants and consequences of child health and illness." The Council on Community Pediatrics of the American Academy of Pediatrics (AAP) expands on this definition and states that community pediatrics is

- A perspective that enlarges the pediatrician's focus from one child to all children in the community
- A recognition that family, educational, social, cultural, spiritual, economic, environmental, and political forces act favorably or unfavorably, but always significantly, on the health and functioning of children
- A synthesis of clinical practice and public health principles directed toward providing health care to a given child and promoting the health of all children within the context of the family, school, and community
- A commitment to use a community's resources in collaboration with other professionals, agencies, and parents to achieve optimal accessibility, appropriateness, and quality of services for all children and to advocate especially for those who lack access to care because of social, cultural, geographic, or economic conditions or special health care needs
- An integral part of the professional role and duty of the pediatrician

A FOCUS ON ALL CHILDREN IN THE COMMUNITY

In part because of the successes of our predecessors, communities today are different from those of the past. Immunizations and improved living conditions have dramatically changed the types of health challenges that are seen. New legislation has made the world safer in some ways, with seat belt laws and child seats mandatory in many developed countries. Antibiotic coverage, in spite of resistance, has improved the outcome of most infectious diseases in the industrialized world. More sophisticated treatments are now available for premature infants and seriously ill children. The resulting effect on communities includes dramatically lower perinatal mortality and child death rates.

However, communities today are not necessarily healthier than in previous decades. Obesity is pandemic. Asthma has dramatically increased, partially in response to environmental changes.

Social trends in communities affect optimal child development. Two-parent working families may have less face-to-face time, but programs such as adequate child care and family leave help support parental involvement. Fathers are now much more often involved in the birth of their babies and care of their children.

Much of the effectiveness of pediatric care has been based on the individual clinical encounter, the opportunity for physicians to promote health one by one with children in their practices. But as the problems and morbidities that affect children change over time, the individual clinical encounter by itself has become less adequate in promoting optimal functional health in children. Community pediatrics reflects this changing spectrum of pediatric practice. New morbidities include increasing numbers of children with chronic health care needs, obesity, children's mental health conditions, exposure to environmental hazards, substance abuse, lack of school readiness, and family dysfunction. Facing these new challenges requires pediatricians to broaden their focus. While pediatricians have always cared for children within the context of their families and their practices, now there is the need to incorporate a perspective that charges pediatricians with considering all children in the community.

A RECOGNITION THAT MANY FAMILY AND COMMUNITY FACTORS AFFECT CHILDREN'S HEALTH AND FUNCTION

A leading child advocate and one of the founders of pediatrics, Abraham Jacobi, MD (1830–1919) recognized that children are best understood within the

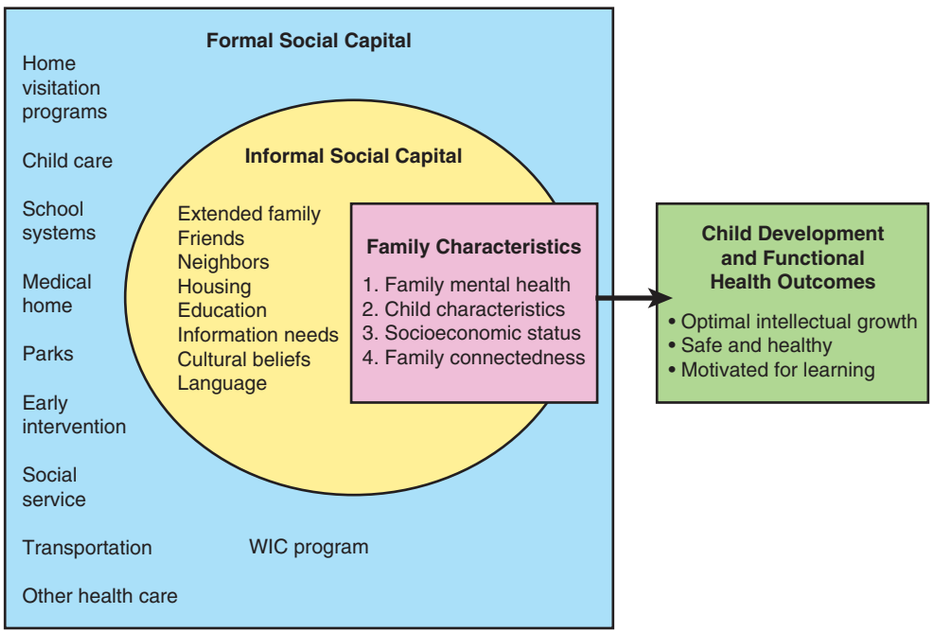

Figure 21-1 Community context in which children grow and develop.

interlinking contexts of biology, family, and community. Children and their families are surrounded by a milieu of factors that negatively and positively affect functional outcome. The religious and cultural beliefs of the family lay a foundation on which childhood develops. Social isolation, the built environment, adequate child care, schools, and playgrounds all affect health. Children in poor communities experience the well-documented deleterious effect of poverty on their well-being. Certain populations, such as farm workers, immigrants, and foster children, are at increased risk for poor health. Substantial disparities exist in access to health care among populations within communities and provide a special challenge to pediatricians. Because legislative and social policies affect child health, pediatricians should advocate for universal access to quality health care for all children.

Positive physical and emotional development depends on the health of families and communities. These positive supports are referred to as social capital, both formal and informal, that impart a sense of health, safety, and well-being, and promote a supportive environment for families of all backgrounds. The pediatric medical home is part of a broad range of social supports that comprise a family's social capital (Figure 21-1).

A SYNTHESIS OF CLINICAL PRACTICE AND PUBLIC HEALTH WITHIN THE CONTEXT OF FAMILY, SCHOOL, AND COMMUNITY

Essential to the concept of community pediatrics is the incorporation of public health methodology into clinical medicine. The US Surgeon General develops a framework for prevention known as the Healthy People program every 10 years. Goals and objectives provide targets for positive change for many health indicators in the United States, including focused goals on maternal and child health issues (see Box 21-1). Using a public health approach, states, communities, professional organizations, and community pediatricians are instrumental in ensuring that these goals can be met. A public health approach is driven by the use of community data (epidemiologic, demographic, and economic) as the basis of understanding child health. Data help identify particular community-based strategies that improve child health potential and guide further activities. Data systems also instruct health care systems in quality improvement activities that promote efficiency and efficacy in the delivery of child health.

BOX 21-1 2020 Leading Health Indicators

- Access to health services
- Clinical preventive services
- Environmental quality
- Injury and violence
- Maternal, infant, and child health
- Mental health
- Nutrition, physical activity, and obesity
- Oral health
- Reproductive and sexual health
- Social determinants
- Substance abuse
- Tobacco

School health is often a component of community pediatric initiatives, and schools work interactively with public as well as private physicians. School nurses can be useful in assisting community pediatricians with the management of chronic health conditions. Schools themselves often provide access to health care services for disadvantaged populations, thereby reducing disparities in access to health care, and provide a unique opportunity for the provision of mental health services. Schools can be effective in spreading public health messages that lead to population-based changes in health behavior.

A COMMITMENT TO USE COMMUNITY RESOURCES TO PROMOTE OPTIMAL CHILD HEALTH

Community pediatricians collaborate with professionals in other disciplines on child health and development issues. Opportunities for collaboration can take place in a variety of formats, such as colocation of services with providers from other disciplines, formal project relationships, or the development of community resource guides to assist care coordination and management. Informal ways of getting to know other service providers in the community, such as professional social gatherings, visits to service sites, or preparation of resource directories have assisted the identification of valuable adjunct services. Regardless of methodology, pediatricians and their staffs should educate themselves regarding the availability of community resources that augment their own efforts to improve the health and well-being of their patients.

Collaborative care has the potential to help families through greater knowledge transfer on health topics, improved access to formal and informal sources of social support, and access to other community-based services. Collaborative initiatives work best when implemented using a strength-based approach. Pediatric collaborative efforts should reflect the importance of the medical home in children's and families' lives and not undermine the therapeutic physician-patient relationship. Collaborative services with other professionals should not be viewed as a substitute for the important role of physicians in their patients' lives, but as a means to augment services.

Increasingly, collaborative arrangements take the form of a team of caring professionals providing a wide range of services for children. In addition to nurse practitioners, many pediatric offices now include on-site mental health providers, social workers, care coordinators, lactation consultants, healthy development specialists, and even home visitors. In some practices, designated case managers or care coordinators facilitate a team approach, as they often become experts on the nature of community services and can assist with linkages for appropriate care. Care coordination services are often cost efficient for practices and helpful in ensuring good outcomes. In some communities, care coordination services are pooled among several practices, often with public health or managed care support.

ADVOCATE FOR THOSE WHO LACK ACCESS TO CARE

Advocacy can mean working with legislators, policy makers, the media, not-for-profit organizations, community programs, and others to improve child well-being, or working to address the needs and issues that affect a particular patient. Examples of successful pediatric legislative efforts include the Child Health Insurance Program Reauthorization Act (CHIPRA), laws requiring seat belt and car safety-seat use, and public funding for important child health programs such as immunizations. Media advocacy involves ensuring that the pediatric perspective is portrayed favorably in various news outlets (eg, community outreach programs). Pediatricians should advocate for neighborhood structures that support optimal health, safety, and development in children and their families. Consulting with school systems, child care facilities, and other local organizations concerned with child well-being provides opportunities for assisting children. Personal advocacy involves making contacts on behalf of a child with schools, insurance companies, home health nurses, and others who can benefit the child. Various organizations of which the pediatrician is a member can be helpful in developing meaningful advocacy activities. For example, state chapters of the AAP often provide leadership and support in the development of advocacy efforts at the state and local level. The Community Access to Child Health (CATCH) program of the AAP is a resource for pediatricians considering advocacy at the local level.

AN INTEGRAL PART OF THE PROFESSIONAL ROLE AND DUTY OF THE PEDIATRICIAN

Caring pediatricians understand the importance of incorporating the community within the scope of their professional responsibility. Unfortunately, funding mechanisms underlying care often don't appreciate the importance of any activity outside of the individual clinical encounter. As patient-centered medical homes are being established, changes in the way traditional primary care is reimbursed are being evaluated. The provision of care management fees or pay-for-performance incentives could help cover extended services. Pediatricians often complain of being inadequately trained in community pediatric techniques. Younger pediatricians report more training in community child health during and before residency than in the past, but still report that their current level of involvement in community approaches to care is inadequate. Regardless of payment and training, however, community pediatrics has become and will continue to be an integral part of the professional role and duty of the pediatrician.

One example of a child health problem amenable to a community approach is the prevention and treatment of obesity. The current approach, based on the individual clinical encounter, has been less than satisfactory because it is not time-efficient for physicians to work one-on-one with children at risk for obesity. Even motivated families and children have difficulty

cooperating with treatment regimens. Recent studies suggest that a community approach has great potential for success in dealing with this issue. Collaboration with nutritionists, home visitors, public health officials, and parenting specialists can provide the basis for a successful support system for children at risk. An understanding of community factors that lead to weight problems, such as advertisements during children's TV programs, lack of opportunities for exercise, and easy availability of high-calorie food with poor nutritional value, opens the door to potential strategies. Advocacy using the media has the potential to promote healthier lifestyles through such means as public service announcements concerning the effect of TV, the caloric value of foods, and the importance of regular exercise in the maintenance of optimal body weight. Working with school health services to counsel students and school administrators may ensure that all children have the opportunity for regular physical activity and appropriate nutrition in school.

Community pediatrics has been an integral part of child health services since the very beginning of the specialty of pediatrics. But, with changing morbidities and the social, economic, and psychologic problems facing children, it has taken on a renewed importance in the daily routines of pediatricians. Only by recognizing the contextual nature of pediatrics within a variety of factors affecting health, and only by working with the broader community, can we achieve satisfactory results.

TOOLS FOR PRACTICE

Community Advocacy and Coordination

- *Adolescent & School Health* (Web page), Centers for Disease Control and Prevention (www.cdc.gov/healthyyouth/schoolhealth/index.htm)
- *Building the Legacy: IDEA 2004* (Web page), US Department of Education (idea.ed.gov)
- *Connected Kids Clinical Guide* (booklet), American Academy of Pediatrics (www2.aap.org/connectedkids/ClinicalGuide.pdf)
- *Healthy People 2020 Count Data Resources* (Web page), US Department of Health and Human Services (www.healthypeople.gov/2020/county-data-resources)
- *Healthy People 2020 Evidence-Based Resources* (Web page), US Department of Health and Human Services (www.healthypeople.gov/2020/tools-resources/Evidence-Based-Resources)
- *Healthy People 2020 Program Planning Guide* (Web page), US Department of Health and Human Services (www.healthypeople.gov/2020/tools-and-resources/Program-Planning)
- *NACCHO Toolbox* (Web page), National Association of County and City Health Officials (www.naccho.org/toolbox)
- *The National School Lunch Program* (NSLP) (Web page), US Department of Agriculture (www.fns.usda.gov/nslp/national-school-lunch-program-nslp)
- *State School and Health Resources* (Web page), American Academy of Pediatrics (www2.aap.org/sections/schoolhealth/contactmap/section_contacts.cfm.htm)

Engaging Patient and Family

- *Child Care Aware Parent and Family Resources* (Web page), Child Care Aware America (childcareaware.org/parents-and-guardians/resources)
- *Community Health Online Resource Center* (directory), Centers for Disease Control and Prevention (nccd.cdc.gov/DCH_CHORC)
- *Data Tools* (Web page), National Center for Children in Poverty (nccp.org/tools)
- *Frequently Asked Questions About Section 504 and the Education of Children With Disabilities* (fact sheet), US Department of Education (www.ed.gov/about/offices/list/ocr/504faq.html)

Practice Management and Care Coordination

- *Care Coordination Toolkit* (booklet), National Center for Medical Home Implementation (www.medicalhomeinfo.org/downloads/pdfs/CareCoordinationToolkit06.pdf)

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Chapter 22

PROMOTING THE HEALTH OF YOUNG CHILDREN

David P. Steffen, DrPH, MSN; Jill Kerr, DNP, MPH; Jonathan B. Kotch, MD, MPH

INTRODUCTION: WHAT TODAY'S YOUNG CHILDREN FACE

The demographics of young children in the United States have changed dramatically during the past 15 years, and these changes are not slowing. According to the Pew Research Center, since 2000 more than 90% of population growth has been among racial and ethnic minorities, many of whom are immigrants. Most of this growth (56%) is from Hispanic births. Hispanics represent the largest population of minority infants (26.1%), followed by African Americans (13.7%) and Asians (4.4%). The US minority population is younger than the white population and has a large proportion of 20- to 34-year-old women who are at the height of their childbearing years. The prime childbearing age for whites and Asians is the late 20s

and early 30s. For African Americans and Hispanics, the peak is the early 20s. Hispanics have the highest total fertility rate of any group at 2.4, followed by African Americans at 2.1. Whites and Asians have the same rate, 1.8.

This growth in the minority population of the United States is important to child health trends because a large proportion of young racial and ethnic minority children live in low-income families. Although only 29% of Asian children and 35% of whites fall into the low-income category, 70% of blacks and 66% of Hispanics are living in low-income families. This effect of poverty is exacerbated by the fact that blacks and Hispanics are slightly more likely than Asians or non-Hispanic whites to be living in areas of concentrated poverty, making opportunity hard to find and magnifying the effects of the social determinants of health.

POVERTY AND TOXIC STRESS

Toxic stress is strongly associated with income level. Nearly 67% of children with family incomes less than 100% of poverty have had an adverse childhood experience, as opposed to 27% of children with family incomes above 400% of poverty.

Toxic stressors may include child abuse or neglect, parental substance abuse, maternal depression, witness to domestic violence, and separation from loved ones. Many children exposed to these stressors go on to develop physical and mental health problems, even into adulthood. Some will be counted among the 11% to 20% of children in the United States who have a behavioral or emotional disorder. Emergency department (ED) visits increased by more than 20% for children 1 to 4 years of age between 2006 and 2011. This increase was likely related to an almost 61% increase in ED use for behavioral disorders, accounting for more than 75% of the patient visit increases for 1- to 4-year-olds.

According to the National Center for Children in Poverty, there are 7 risk factors associated with poverty that contribute most to young children's adversity:

- Being born to a teen mother
- Being born to a single parent
- Being born to a parent with low education
- Living in a large family
- Experiencing residential mobility
- Living in a household without an employed parent
- Living in a household without English speakers

Of the 37 million children younger than 6 years, 39% do not have any of the risk factors; 41% have 1 or 2; and 20% have 3 or more. The Annie E. Casey annual *Kids Count Data Book* tracks a total of 16 child health indicators with 4 subindicators in each of 4 categories: economic well-being, education, health, and family and community.

Trends in these categories from 2005 through 2012 were highlighted with the release of the 2014 *Data Book*, which marked 25 years of publication. Between 2005 and 2012 there were a number of encouraging trends: preschool attendance went up, as did high school graduation rates; there were small drops in child and teen mortality and in very low birth weight; the teen birth rates hit historical lows; and health insurance coverage increased slightly. However, there were discouraging trends as well. Economic well-being has not recovered from the recession, with 22% of children still living in poverty and more concentrated pockets of low income. The economic recovery is not trickling down to provide jobs for heads of poor households. The fraction of children living in households with a solo parent increased. The most distressing trend was the continued chokehold that poverty has on almost one-fourth of US children's families. Notably, the indicators do vary significantly by state; these differences can be followed on individual state data reports.

RATIONALE FOR INTERVENTION DURING EARLY CHILDHOOD

A strong rationale exists for the very earliest of interventions in the development and growth of children—the proverbial "first 1,000 days"—as the marginal effect on child health of therapeutic interventions diminishes over time. The "loss aversion" argument is also compelling: namely, we as a society cannot tolerate the great loss that would result from failure to implement relatively simple interventions early in life.

A new index has been developed to address the social determinants of health—the "The Child Opportunity Index." It is designed to improve collaboration between community development agencies and public health in the 100 largest US metropolitan areas. In various neighborhoods, the researchers measured the extent of opportunity, ethnic mix, and income mix. They found that the lowest opportunity neighborhoods were most often populated with people of color—40% of black and 32% of Hispanic children—as opposed to less than 10% of white children. This is even more sharply felt in cities with high levels of segregated housing. The measures they used included the categories of social and economic opportunities (6 indicators), health and environmental opportunities (6 indicators), and educational opportunities (8 indicators). The authors think that this may be useful for health care institutions and accountable care organizations who desire to move into a metropolitan area but want to know how difficult it will be to meet their community benefit obligation in that community. A similar sort of investigation was performed on communities with Health Legacy Foundations to ascertain whether they were situated in communities that were relatively well-off in order to justify spending their funds elsewhere. The researchers found that Health Legacy Foundations by and large are in poorer resourced communities, so redistribution is not a likely source of money.

PROMOTING THE HEALTH OF YOUNG CHILDREN

There are many different educational, medical, and social service settings with a variety of professionals, paraprofessionals, and laypersons involved in trying to promote positive responses and resilience, prevent or ameliorate adverse stress, or rehabilitate those young children who have suffered from toxic stress.

Some of these are embedded in clinical pediatrics; some are community-wide programs.

Chapters 31 through 45 describe strategies to promote health through the medical home, including early literacy promotion (talking, singing, and reading; Reach Out and Read); evidence-based programs to foster positive parenting (eg, Triple P, Incredible Years); and counseling around sleep, special time with parents, healthy weight, physical activity, sexuality, and limiting the use of electronic media. Chapter 79, Children in Poverty, describes a number of public programs designed to ameliorate the effects of poverty, including Temporary Assistance for Needy Families, the Earned Income Tax Credit, Child Support, Child Care Subsidies, Supplemental Nutrition Assistance Program (Food Stamps), and the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC). Other chapters describe the care of other special populations: Chapter 68, Children Exposed to Adverse Childhood Experiences; Chapter 69, Caring for Families New to the United States; Chapter 70, Adoption; Chapter 71, Children of Divorce; Chapter 72, Children in Foster or Kinship Care; Chapter 77, Children in Military Families; and Chapter 78, Homeless Children. Part 3 of this book addresses prenatal care, and Part 4 addresses assessment and stabilization at delivery and care of high-risk infants, including those with depressed mothers. These are critical strategies to protect and promote the health of young children.

This chapter focuses on early home visiting programs, medical-legal partnerships, initiatives to improve the health and safety of out-of-home care, Early Intervention programs, and Head Start. It also outlines the role of pediatricians in addressing the needs of young children at a community level.

MATERNAL, INFANT, AND EARLY CHILDHOOD HOME VISITING PROGRAMS

As evidence of the critical importance of intervening early in vulnerable children's lives has mounted, so has interest in early home visitation programs. These programs were initially funded predominantly by small private and public sources, but early home visiting that meets certain outcome criteria has now gained Affordable Care Act (ACA) support and other public and private financing, indicative of the confidence that funders have developed in family-focused health interventions. The Maternal, Infant, and Early Childhood Home Visiting Program (MIECHV), administered by the Health Resources and Services Administration (HRSA) and the Administration for Children and Families, funds states, territories, and tribal entities to develop and implement evidence-based home visiting programs. These programs use models proved to improve maternal and child health and produce other positive outcomes, such as decreases in child abuse and neglect; decreased injuries; better speech development and readiness for school; reductions in behavioral problems, depression, and substance abuse; and, for mothers, fewer incidents of substance abuse, increased maternal employment, better spacing of births, and decreased necessity of public support.

Programmatic goals, target populations, and interventions may vary, but all programs are delivered in homes, by staff trained to improve knowledge, beliefs, and behaviors. By seeing the young child interacting in the home environment with family, the home visitor can better assess and respond to real needs, develop tailored strategies, and coordinate services for individual families. This is far superior to standardized, "one-size-fits-all" institutional treatment and appointment scheduling. One major opportunity from visiting is education regarding online health-related messages and websites, including those of the American Academy of Pediatrics (AAP). Many adolescents are used to communicating by cell phone, and the home visitor can introduce the many "apps" that give opportunities for health-related reminders and information, such as Text4Baby, Zero to Three, Bright Futures, the Incredible Years, Triple P-Positive Parenting Program, FamiliasUnidas, Autism Navigator, and many other information sheets and resources developed by the AAP and Centers for Disease Control and Prevention (CDC).

Variation in Programs

The implementation of home visiting programs varies widely. Some programs begin during pregnancy, such as Nurse Family Partnership (NFP) and Early Head Start, whereas others begin when a child is born or even later. The length of most programs is 2 to 4 years, which ensures there will be adequate time to develop a strong relationship between mother, child, and home visitor. The background for home visitors' educational preparation ranges from professionals with bachelor's or master's degrees in nursing to paraprofessionals who live in the communities being served, many of whom possess language and cross-cultural skills that match those of the clients being served. Paraprofessionals have not been proved to be as effective as professional nurses in general home visiting. However, home visitation by community health workers has recently been shown to be cost-effective in some specialized areas for intervention, such as reducing asthma-related hospital care in children.

The varying structure of programs is based on disparate levels of resources and differing goals. Some programs, such as Healthy Families America (HFA), attempt to prevent child abuse and neglect by improving parenting skills and promoting healthy child development. Other programs focus on improving mothers' lives by supporting their efforts to return to school, to postpone subsequent pregnancies, and to earn a living. Programs emphasizing the personal relationship between parents and home visitors, such as Parents as Teachers (PAT), Home Instruction of Parents of Preschool Youngsters (HIPPY), and Parent-Child Home Program (PCHP), can bridge the isolation between families and their communities. By providing social support and practical assistance, home visitors attempt to stimulate and nurture changes in parents' attitudes, knowledge, and behavior.

Home Visitation Program Examples

In 2005, the federal government reauthorized MIECHV funding for 17 home visitation models they deemed "evidence based." The Colorado-based nonprofit

Nurse Family Partnership model of home visitation, the Nurse Home Visitation Program, is the most rigorously evaluated and widely replicated visitation model. The model is constantly being refined and re-evaluated under the guidance of pediatric researcher David Olds. It supports Eckenrode and colleagues' argument that altering a mother's life course has important implications for her children. A mother's ability to assume responsibilities associated with a steady job and postpone a second pregnancy may make it possible for her to emerge from poverty and focus her efforts on her child. A 19-year follow-up of a randomized trial showed that girls born to high-risk mothers who had Nurse Home Visitation Program model prenatal and infancy home visitation had fewer subsequent pregnancies, were more likely to defer second births, spent fewer months on welfare or receiving food stamps, and had fewer problems with arrests and substance abuse than the mothers who did not receive nurse home visits.

The Healthy Steps Program is a medical home visitation project. There are 70 such programs across the country in which young at-risk children are required to be seen in their pediatric home by a specially mandated additional staff person, the Healthy Steps Specialist. The specialist has advanced training in one or more pediatric fields and ensures that children receive appropriate development screening and other services designed to assure emotional health, in particular.

Involvement of Fathers

Until recently the primary focus of home visiting had been almost exclusively on the mother-child relationship. During the past decade, however, there has been outreach to fathers and other family members. The NFP found that nurse home visitation had significantly more fathers in attendance than did paraprofessional home visitation. Recently Holmberg and Olds reported that father attendance in home visiting was associated with factors such as the number of completed maternal home visits, maternal cohabitation with the partner, being married, and white, non-Hispanic race.

Because the presence of the father is a positive influence on the child's and mother's life (except when he is abusive), it is important to engage him in the family parenting and family functioning process. Paternal presence has generally been low—between 2% and 32% of visits in the Nurse Home Visitation Program. Reports indicate that some success in engaging men has come from having more "male" types of activities, such as sporting events, outdoor events such as cookouts and picnics, coaching, and martial arts; fathers have been drawn in and then been integrated into healthy parenting topics and principles of successful fatherhood.

In their study of the differences in father's frequency of attendance, Holmberg and Olds reported that more of the difference was attributable to intangible clinic and nurse visitor characteristics, most likely the skill of the home visitor. This brings attention to the vital importance of the quality of interaction between visitor and family, particularly the visitor's ability to bring in and involve the father in the conversation. Holmberg and Olds conclude that "the ability to remain interpersonally available to the mother and father in the same visit, attitudes about the role of fathers in the program, skill in advocating for father involvement, comfort and working with fathers will be important next steps for research in this area" and further research is needed on father participation and "organizational, team, and nurse factors . . . promising targets of intervention increasing safe, nurturing father involvement and home visits." Dr. Olds is increasing efforts to retain nurses: continuity of personnel enhances technical implementation of the program and strengthens the relationship of the nurse with parents. Mothers are reportedly 7 to 8 times more likely to drop out if they lose their current nurse visitor.

Attaining Other Outcomes

Results from a variety of programs' evaluations document some change in parents' attitudes as a result of the home visiting programs, and often in their behaviors. Despite promoting the importance of prenatal care and the use of preventive health visits, none of the 6 evaluation studies found improvements in immunization rates or number of well-child visits. Results for assessments of children's development and behavior similarly suggested only modest improvement.

All home visiting programs depend on changes in parents' behavior to nurture children's health and development. However, the complexity and variety of the family situations affect the consistency with which a home visiting program can be implemented. To expand and develop home visitation, improved methods are needed to evaluate programs. This includes examining context, service intensity and "units," family engagement, and training and characteristics of home visitors. There needs to be an accurate understanding and measurement of risk. Assessment of the involvement of family members in addition to the mother and child requires further exploration. Strengthening home visitation programs to produce better outcomes for the children and families requires ensuring that the programs are an integrated component of a system of support rather than a separate intervention model. The results from evaluations of home visiting programs to date suggest that expectations for home visiting without clear standards of technical fidelity and clear, faithful commitment to clients can only be modest and, most important, that home visiting cannot be the only strategy for serving families with young children at risk for poor health and development.

Universal Home Visiting

Buoyed by the predominantly positive findings and the experiences of other countries, some advocates in the United States have proposed universal nurse home visiting of families with newborns. The main reason for this is that even the most experienced and educated parents have difficulty with and questions regarding parenting their children, each of whom may have a different temperament. Universal home visiting has the potential to remove the stigma of being "high risk," provide a common experience for all mothers in the region, and foster open dialogue about parenting and the care of children.

MEDICAL-LEGAL PARTNERSHIPS

Medical-legal partnerships have been developing since 1993. According to the National Center for Medical Legal Partnerships, there are currently 125 hospitals, 123 health centers, 26 medical schools, 36 residency programs, and 34 law schools in the United States that have adopted the model. O'Toole and colleagues demonstrated that residents who worked in clinics with social and legal resources had confidence to screen for social determinants of health.

Partnerships are being formed between pediatricians and legal aid, law school students, and *pro bono* lawyers in the community. Some are colocated in the clinical setting. They may provide direct legal aid or align strategies with health care services. The model can help improve young children's health by dealing with legal needs that affect well-being. Some examples of legal needs that affect health are government entitlements, housing (including mitigation of lead exposure), legal status, domestic violence, and custody issues.

INITIATIVES TO IMPROVE HEALTH AND SAFETY IN CHILD CARE

Nonparental child care comes in various types, and any given child may participate in more than one type of nonparental care. According to the US National Household Education Survey, approximately 60% of US children 0 to 5 years who are not in kindergarten are in some form of regular, nonparental care every week. (Of course, older children may be in group child care before and after school, but their care is outside the scope of this chapter.)

In most states, nonparental care of 3 or more unrelated children for 4 or more hours per day at least once a week is considered to be the kind of child care falling under state regulatory authority. A facility providing group care for fewer than 6 children 0 to 5 years of age is considered a child care home, whereas a facility providing group care for 6 or more such children constitutes a child care center, regardless of the shape of the building in which the care is given. It is important, however, to recognize that these definitions may vary by state. Community-based pediatricians should be aware of the number, location, and variety of early care and education programs operating in their service areas.

All states have some way of measuring child care quality (quality rating and improvement systems, or QRIS), and in some cases states may attach benefits to higher quality ratings, such as higher rates for children who are eligible for public subsidy. Pediatricians should be aware of how child care centers and homes are rated in order to be better positioned to help families choose the best child care experiences for their children. Information about the availability and quality ratings of local child care facilities can be obtained from Child Care Resource and Referral Agencies (CCR&Rs). (See www.childcareaware.org for your state and local CCR&R.) More active involvement in the QRIS process at the local or state level is an option for pediatricians who are willing to contribute their time to improving the quality of early care and education overall. Children's health and safety in child care is an important component and an essential basis of quality because physical, cognitive, and social-emotional development are inextricably linked and contribute to children's readiness for school. The pediatrician can be a powerful advocate for health and safety in child care in the QRIS and state regulatory processes.

OPPORTUNITIES FOR HEALTH PROMOTION IN EARLY CARE AND EDUCATION PROGRAMS

For 60% of American children, early care and education programs are the best places to reach groups of children and their families between birth and kindergarten entry. The opportunities for promoting health, safety, and psychosocial development are enormous. All pediatricians are urged to discuss child care as part of the AAP recommended schedule of anticipatory guidance. In addition, the community-based pediatrician or designee can support individual child care facilities or the early care and education community in many ways.

Infectious Disease Prevention

Infectious diseases (primarily upper respiratory and gastrointestinal infections) are more prevalent among young children cared for in group out-of-home care settings than in those cared for in their homes, but there are proven ways of reducing the transmission of infectious disease. Pediatricians can participate in planning and providing trainings for child care providers on how to prevent infectious disease transmission and how to control an outbreak in the child care facility should one occur. For children in child care who become sick, pediatricians and their designated mid-level providers should understand state child care regulations about exclusion from care in order to advise parents when it is recommended that children stay home and when they can return to group child care.

Allergies and Asthma

Controlling exposure to allergens and asthma triggers is just as important in child care as it is in family homes. The pediatrician or designee can work with child care providers to reduce dust, dander, mold, and other allergens in the facility. This includes familiarity with Integrated Pest Management techniques for controlling vermin using a minimal amount (if any) of pesticides in or near facilities where children are cared for. In the cases of children with asthma or allergies, child care providers must be comfortable with the use of inhalers and epinephrine autoinjector (EpiPen). Written orders from a pediatrician are usually necessary; a well-written care plan is essential. In most states, training child care providers in the administration of both prescribed and over-the-counter medications is regulated by the state's nurse practice act, which pediatricians working with child care facilities should understand.

Injury

It is not necessarily the case that children are at greater risk for medically attended injuries in out-of-home child care than they are in their own homes. It is true, however, that injuries in both settings can be reduced further. Most states mandate that injuries requiring medical attention be reported by the child care provider to a designated agency. Using data from such reports, investigators were able to show that strengthened playground safety regulations significantly reduced such medically reported injuries in one state. The pediatrician or designee can play an active role in developing state policies that mandate that child care facilities subscribe to stringent safety requirements. At the facility level, child care safety advocates can help providers identify and mitigate injury risks. The pediatrician can also counsel parents to discuss safe sleep practices with child care facilities.

Immunizations

Immunization requirements for admission to out-of-home child care are regulated in most states, just as they are for school entry. Thus, children in regulated child care tend to be better immunized than children in family care. Nevertheless, many child care providers lack information about the importance of and the necessity for immunization. Pediatricians or their designees can play a role in raising the awareness of prevention of infectious disease through immunization by participating in the training of child care providers. At the same time, pediatricians need to be aware that state immunization requirements for child care may differ from the recommendations of the Advisory Committee on Immunization Practices.

Nutrition and Physical Activity

In addition to the home and the neighborhood, out-of-home child care is a setting in which childhood overweight and obesity should be addressed. At the policy level, pediatricians and their designees can advocate for regulations to promote breast feeding, control the amount of sweetened beverages and juices and full-fat milk offered to children, establish a minimal level of physical activity, and limit screen time. At the facility level the pediatrician or designee can offer guidance with respect to healthy foods and beverages; encourage safe, active play; and discourage the overuse or abuse of television, computers, tablets, hand-held devices, and the like.

Social-Emotional Health

Expulsion rates from early childhood programs are extremely high, and most of these are because of challenging behaviors. Child care is an ideal setting in which to address children's social, emotional, and behavioral needs before school authorities label them as "children with special needs." Evidence-based classroom teacher training in promoting mental health and responding to challenging behaviors is available (eg, Incredible Years, incredibleyears.com; and the Center on the Social and Emotional Foundations of Early Learning, csefel.vanderbilt.edu), and the pediatrician or designee can encourage child care providers to avail themselves of these programs. Child care can also be a focus around which to organize parenting training. Finally, child care mental health consultants can work with teachers and parents in the child care setting through education, training, and coaching to address the social-emotional needs of young children to improve mental health outcomes and reduce expulsions.

Oral Health

Tooth decay is the most common chronic disease in American children. Child health and child dental health providers can work together to take advantage of oral health care and educational opportunities in child care. The same dental hygiene that pediatricians and designees recommend to parents of infants and young children should be taught to child care providers and teachers. Children old enough to do so should brush their teeth with fluoridated toothpaste after meals and snacks just as they would at home. The nutrition recommendations that address overweight and obesity by eliminating sweets and empty calories from children's diets will also help prevent tooth decay. Finally, dental screening and fluoride sealants may be possible in the facility for children who are old enough.

Child Care Health Consultants

Most states are served by child care health consultants (CCHCs). A CCHC is a child health professional who has "interest in and experience with children, . . . knowledge of resources and regulations and is comfortable linking health resources with facilities that provide primarily education and social services." A fully trained and qualified CCHC can assess the health and safety status of child care facilities; consult collaboratively with child care providers on-site or by telephone or electronic media; help develop or update health policies and procedures; provide referrals for health, mental health, and social needs, including medical homes, children's health insurance programs (CHIPs), and services for special health care needs; consult with a child's primary physician about medications as needed, in collaboration with parents or guardians; interpret standards, regulations, and accreditation requirements related to health and safety; and provide technical advice, separate and apart from the enforcement role of a regulatory inspector. Community-based pediatricians may receive referrals from CCHCs and in turn work with CCHCs, most of whom are nurses, to facilitate the implementation of medical care plans for their patients in out-of-home care. Working together, pediatricians, their designees, and CCHCs can promote quality, health, and safety for child care in their communities.

EARLY INTERVENTION

In 2012, 8% of young children born in the United States weighed less than 2,500 grams or 5½ pounds. In 2011, 6.1 infants per 1,000 live births died before their first birthday. More than one-fourth of children younger than 6 years have a disability.

Pediatricians are specialists in the complex care of children with special health care needs. There is enormous potential and need for the pediatrician to take a central leadership role in care coordination for young children who receive services under the Individuals with Disabilities Education Improvement Act (IDEA).

IDEA is a federal law that dictates how states provide early intervention services and special education to children with special needs. Part C covers infants and toddlers from birth until 3 years old. Services are outlined in an Individualized Family Service Plan (IFSP). Part B covers children after their third birthday until age 21 years with an Individualized Education Plan (IEP), administered by the local education agency.

A child who demonstrates a delay in development, speech, language, or gross or fine-motor skills may be referred for evaluation by the pediatrician, parent, child care center, or hospital. If the child is younger than 3 years, the public health department or other coordinating agency does the initial screening. Between 3 and 5 years of age, the early intervention team of the public school system evaluates the child. If the child's delay was not identified until after kindergarten entry, the K–12 intervention team begins the process.

The evaluation is by a multidisciplinary team (not necessarily including a physician). With parent permission, the child is screened and, if found to have significant delays, referred for a full evaluation. If the child is eligible for Early Intervention (EI) or special education services, the team, in collaboration with the parent, determines which services to recommend (occupational therapy, physical therapy, speech-language therapy, special education) and with what frequency. The IFSP determines whether the services will be in home or at an office. Some states provide services recommended by the IFSP free of charge; others apply fees. The IEP will determine whether the services will be in either a school or child care setting or an EI office. These services are free of charge. IDEA regulations require that all services take place in the "least restrictive environment."

There are many professionals and paraprofessionals involved in developing and implementing the IFSPs and IEPs, including but not limited to social workers, occupational therapists, physical therapists, speech-language pathologists, nurses, psychologists, early childhood special educators, and pediatric specialists. Many pediatricians have a low level of involvement in these processes, and some think that an established diagnosis is necessary before making an EI referral. This perception is associated with decreased referral for children with speech delay, particularly among English language learners, despite parental concern for inappropriate development. Parents may or may not perceive the pediatrician as part of the care team. Without specific parental authorization through the Health Insurance Portability and Accountability Act (HIPAA) or the Family Educational Rights and Privacy Act (FERPA), the pediatrician of a child receiving EI services may be unaware of goals and progress. However, pediatricians can make significant contributions to communication (parents, therapists, and agencies), information exchange, and service delivery coordination. The pediatrician has the ability to request a meeting of the EI team or to visit providers in their workplaces. Attendance at an IFSP or IEP meeting could be done virtually or by phone. At a minimum, parents should be instructed to bring copies of the plans and updates to be part of the child's medical record. If the pediatrician is unaware of the EI system or process, the local Area Health Education Center (AHEC) may be available to provide training.

HEAD START

Head Start is an evidence-based program of the US Department of Health and Human Services, providing comprehensive early childhood education, health, nutrition, and parent involvement services to low-income children and their families. Head Start has personnel to ensure program fidelity: health services coordinators, parent services coordinators, and consultants as needed—nurse health consultants, nutrition professionals, mental health consultants, oral health consultants, home visitors, and social workers.

Head Start's major goal is to ensure that enrolled children enter elementary school with an educational foundation at least equivalent to that of their more economically advantaged peers. In the mid-1990s, in response to the emerging research about the critical importance of development in very early childhood, Early Head Start was developed to serve pregnant women, infants, and toddlers. Eligibility for services is determined by federal poverty level, but factors such as homelessness, child disabilities, foster care, or Supplemental Security Income allow the program to accept some over-income families. Currently, 80% of enrolled children are 3- to 4-year-olds served in preschool classrooms designed to nurture their social-emotional-behavioral development.

Head Start encourages parental involvement as classroom volunteers and requires staff to make home visits. In these ways the program aims to preserve each family's ethnic, cultural, and linguistic heritage. Each Head Start program has a designated staff member, usually with a health-related background, serving as the Head Start Health Services Coordinator. This person systematically evaluates enrolled children's health histories and ensures that each child receives screenings and referrals for preventive medical, dental, vision, nutrition, and mental health services; early intervention; and service coordination. This involves coordinating with other program staff who screen the children to ensure age-appropriate developmental, sensory, behavioral, motor, language, social, cognitive, and emotional skills. These screenings are mandated to be conducted by the 40th day of enrollment. Successful follow-up of findings involves partnering with the child's medical home. If the child does not have a medical home, the coordinator links the child's family to a pediatrician and works to ensure that the child continues to receive comprehensive health care, even after graduating from Head Start.

One-tenth of Head Start enrollment is reserved for children with disabilities, most of whom have hearing

or speech and language impairments. Children with low-incidence, severe disabilities such as blindness, deafness, and intellectual disability are enrolled in the Head Start population in approximately the same proportion as in the IDEA, Part B program for 3- and 4-year-olds. Head Start also enrolls children with feeding tubes and children served by full-time health care aids. For low-income areas and neighborhoods, Head Start is often the only program serving families who have children with severe disabilities.

During the past 50 years, Head Start has served 30 million children and their families. Head Start outcomes have been extensively evaluated, with mixed results. Lee and colleagues looked at data from the Early Childhood Longitudinal Study–Birth Cohort (about 6,950 children) and examined kindergarten readiness (academic skills and socioemotional well-being) in children who had attended Head Start compared with those who had experienced other types of child care (prekindergarten, other center-based care, other nonparental care, or parental care). Head Start participants had higher early reading and math scores than children who had not been in center-based care; however, they demonstrated higher levels of conduct problems than those in parental care. The benefits of Head Start were more pronounced for children who had low initial cognitive ability, children of parents with low levels of education, and children who attended Head Start for more than 20 hours per week. Puma and colleagues found positive comparative health effects; however, they were not retained after the end of third grade.

Many low-income parents with young children have shifted from public assistance to regular employment often requiring longer days and distances. These increased time and travel requirements have resulted in many parents either not getting their child to Head Start at all because of transportation and time issues; or, if they are able to enroll, they and their parents have trouble meeting the Head Start child and parent participation requirements. These factors, in addition to low staff wages, high staff turnover, and lack of training, threaten to jeopardize program quality and participant impact.

Pediatricians can serve as referral agents for Head Start and can connect with local Head Start programs in a variety of ways:

- Designate a staff person to be the coordinator of interactions with Head Start.
- Arrange a meeting early in each school year between the office coordinator and the Head Start Health Services Coordinator.
- Have the designated staff member link the practice to Head Start with business cards and educational pamphlets. Consider formalizing a partnership.
- Become a member of the Health Services Advisory Committee, which is designed to improve services by connecting with the health community.
- Participate in the quarterly, mandated meeting of the Health Services Advisory Committee.
- Participate in the development of IFSPs or IEPs for children from the practice in Head Start.
- Consider arranging a field trip to different types of classrooms (regular education, blended, or self-contained) for pediatric residents, medical students, and office staff.
- Volunteer to accept Head Start patients who do not have a medical home.

THE PEDIATRICIAN'S ROLE

In addition to their critical role as health care providers to young children, pediatricians can participate in (and, in many instances, lead) community health improvement processes. The CDC is a good source for several resources that form the foundation for these processes. The June 2011 version of *Principles of Community Engagement* provides an excellent chart of the continuum of levels of respectively engaging with communities and a series of strategies for becoming involved (www.atsdr.cdc.gov/communityengagement/pce_what.html). The CDC *Guide to Clinical Preventive Services* and *Guide to Community Preventive Services* provide evidence-based strategies vetted by the US Preventive Health Services Task Force that can be used competently both in the clinical and community settings.

The pediatrician can also be a leader in identifying the many evidence-based programs that, when invested in sufficiently and run effectively, are successful in removing roadblocks to children's health. Given the myriad of programs and interventions available, success is highly contingent on quality of implementation, evaluation, and accountability. When vetted interventions are managed well, scaled correctly, and held accountable for results, health effects can be maximized.

Pediatricians can serve as medical advisers to individual child care centers or members of state child care regulatory bodies. Pediatricians can also serve as child advocates, working with other stakeholders to develop and implement policies that promote the health of young children and their families and to protect them against adverse stressors. Most states have a pediatrician member of the AAP chapter serving as the state Chapter Child Care Contact (CCCC). Each CCCC is charged with mobilizing and sustaining efforts to improve the health and safety of children in child care and engage parents in discussions about quality care and their options. The CCCC also serves as a liaison between his or her state chapter and the national AAP regarding early care and education topics and initiatives. Pediatricians are encouraged to work with their CCCCs to increase their involvement in child care activities. See www.healthychildcare.org/cccc.html for more information.

SUMMARY

A growing number of young children in the United States live in poverty—the most powerful social determinant of health. Pediatricians should be aware of public programs to mitigate the effects of poverty and its many associated toxic stressors that contribute to poor health outcomes. Chapter 79, Children in Poverty describes a number of these programs: Temporary Assistance for Needy Families, the Earned Income Tax Credit, Child Support, Child Care Subsidies, Supplemental Nutrition Assistance Program (Food

Stamps), and the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC). Other chapters of this text describe the critical strategies of prenatal care, safe birthing, care of depressed mothers, and care of special populations (children exposed to adverse childhood experiences, children new to the United States, adopted children, children of divorce, children in foster or kinship care, children in military families, and homeless children. Still other chapters focus on promoting the health of young children in the context of primary care. The current chapter expands on several community-based approaches to improving the health of young children: maternal, infant, and early childhood home visiting programs; medical-legal partnerships; initiatives to improve the health and safety of out-of-home child care; the Early Intervention program; and Head Start. Pediatricians can improve the health of young children by ensuring that children and families who can benefit from these programs receive them. Pediatricians can also be effective leaders of and participants in processes to improve the health of young children at the community, state, and national levels.

TOOLS FOR PRACTICE

Community Advocacy and Coordination

- *Caring For Our Children: National Health and Safety Performance Standards; Guidelines for Early Care and Education Programs,* 3rd ed (e-book), American Academy of Pediatrics, American Public Health Association, National Resource Center for Health and Safety in Child Care and Early Education (cfoc.nrckids.org)
- *Center on the Social and Emotional Foundations of Early Learning* (Web site), Center on the Social and Emotional Foundations of Early Learning (csefel.vanderbilt.edu)
- *Healthy People 2020 Evidence Based Resources* (Web site), Healthy People (www.healthypeople.gov/2020/tools-resources/Evidence-Based-Resources)
- *Healthy People 2020 Program Planning Guide* (Web page) Healthy People (www.healthypeople.gov/2020/tools-and-resources/Program-Planning)
- *Healthy People 2020 Count Data Resources* (Web page) Healthy People (www.healthypeople.gov/2020/county-data-resources)
- *State Licensing and Regulation Information* (Web page), National Resource Center for Health and Safety in Child Care and Early Education (nrckids.org/index.cfm/resources/state-licensing-and-regulation-information)

Engaging Patient and Family

- *Child Care Aware Parent and Family Resources* (Web page), Child Care Aware (childcareaware.org/parents-and-guardians/resources)
- *Community Health Online Resource Center* (handouts), Centers for Disease Control and Prevention (nccd.cdc.gov/DCH_CHORC)
- *Head Start and Early Head Start* (Web page), US Department of Health and Human Services (eclkc.ohs.acf.hhs.gov/hslc/hs/about)
- *National Center for Children in Poverty Data Tools* (fact sheet), National Center for Children in Poverty (nccp.org/tools)

AAP POLICY

American Academy of Pediatrics Committee on Psychosocial Aspects of Child and Family Health, Committee on Early Childhood, Adoption, and Dependent Care, and Section on Developmental and Behavioral Pediatrics. Early childhood adversity, toxic stress, and the role of the pediatrician: translating developmental science into lifelong health. *Pediatrics.* 2012;129(1):e224–e231 (pediatrics.aappublications.org/content/129/1/e224)

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Chapter 23

PROMOTING THE HEALTH OF SCHOOL-AGED CHILDREN

Barbara L. Frankowski, MD, MPH; Howard Taras, MD

It takes a village to raise a child.

AFRICAN PROVERB

In 1996, then–First Lady Hillary Rodham Clinton published a book titled *It Takes a Village: And Other Lessons Children Teach Us,* thus popularizing this proverb. In this book, Clinton presents her vision for the children of America, focusing on the effect individuals and groups outside the family have, for better or worse, on a child's well-being, and advocating for a society that meets all of a child's needs. In 1997, America's Promise Alliance (www.americaspromise.org) was founded, with Retired General Colin L. Powell as the Chairman. The Alliance is committed to seeing that all children have access to the fundamental resources they need to succeed—the Five Promises: *Caring adults* in their lives, as parents, mentors, tutors, and coaches; *safe places* with structured activities in

which to learn and grow; a *healthy start* and healthy future; an *effective education* that equips them with marketable skills; and an *opportunity to give back* to their communities through their own service. Children who receive at least 4 of the Five Promises are much more likely than those who experience none or only one Promise to succeed academically, socially, and civically. They are more likely to avoid violence, contribute to their communities, and achieve high grades in school. Receiving at least 4 of the Five Promises also seems to mitigate gaps across racial and economic boundaries. To experience the full power of the Promises, young people must experience these critical supports throughout their lives—in their families, at schools, and out in their communities.

Pediatricians support children and families in achieving these goals. *Bright Futures: Guidelines for Health Supervision of Infants, Children, and Adolescents,* 3rd edition, gives priority to the discussion of school, development and mental health, nutrition and physical activity, oral health, and safety at every visit. For the school-age child, all these discussions need to include the community in which the child is growing. How does the community contribute to a child's physical health and safety? Are there sidewalks, playgrounds with safe equipment, after-school programs, and easy access to healthy food? How does the community contribute to a child's development and social/emotional health? Are there opportunities for social interactions (sports, boys and girls clubs, faith-based organizations, social services)? Pediatricians need to be aware of the context beyond the family that is supporting the child. They can also be advocates for improvement of their communities. For school-aged children, the most influential community setting is the school. Since 98% of school-aged children attend public, charter, or private school, it is not surprising that schools have an enormous influence, both positive and negative, on the health and well-being of our nation's children. The nature and quality of school health programs are germane to primary care physicians' success with disease management as well as illness and injury prevention. Moreover, pediatricians can influence the nature and quality of school health programs. Pediatricians need familiarity with how schools work, knowledge of how to work with schools on behalf of their patients, and knowledge of advocacy techniques that help improve school health programs for all students in a community to influence the health of their own school-aged patients and of all youth in a community.

UNDERSTANDING COMPREHENSIVE SCHOOL HEALTH

One of the most widely used models for school health goals in the United States is the Coordinated School Health Program, a model originating in and endorsed by the Division of Adolescent and School Health at the Centers for Disease Control and Prevention (CDC). The model recognizes 8 major components to any coordinated school health program. One example of the logic that makes the term "coordinated" applicable to a school health program is this—it is counterproductive to teach students about proper nutrition in the classroom if they are offered few healthy choices in the cafeteria. It is equally nonsensical to encourage school counselors and other staff to help students with emotional issues reach appropriate mental health services if staff members themselves do not feel supported by school personnel policies for their own mental health needs. Coordination among all 8 components of a school health program strengthens each of them. The 8 components of a coordinated school health program are described below in terms of what is recommended for schools and how a primary care physician can relate to each component. Further details of each component are available in 2 publications of the American Academy of Pediatrics (AAP)—*Health, Mental Health and Safety Guidelines for Schools,* and the sixth edition of *School Health Policy & Practice*.

1. Health and Safety Education

Under ideal circumstances, health education would be part of any school district's core academic curriculum and have the same budgetary and scheduling priority as literacy, mathematics, and other traditional subjects. Not surprisingly, such a situation is highly atypical. Among physicians and other providers of primary care for school-aged children who recognize this predicament, there are some who try to correct the situation by volunteering to teach a health class (eg, a nutrition class or a class on prevention of drug abuse). While this is well-intended, often enjoyed by students and lecturers, and possibly successful at increasing short-term knowledge of healthful practices, such interventions are unlikely to change student health behaviors. Schools must be encouraged to adopt health and safety curricula that have demonstrated effectiveness in changing student behavior. Research has shown that, to be effective, a curriculum should be planned and sequential (ie, each class builds upon skills and knowledge taught in a previous class), be interactive, have skills-based instruction, optimally involve the family, and be consistent with established health education standards. While classroom teachers may appropriately teach health education in elementary schools, certified health education teachers are necessary in secondary schools because of the complexity of teaching methodology required at this stage, as well as the complexity of the content. Ideally, health education is integrated with other content areas.

Content areas over the course of the 12 years should include prevention of tobacco, alcohol, and other drug use; growth, development, sexuality, and family life; personal and oral health; injury prevention and safety; violence prevention; nutrition; physical activity; Internet safety; and use of social media. The emphasis on some aspects of health over others should vary with a community's unique needs (eg, local injury rates, pregnancy rates, or nature of drug abuse). Pediatricians should consider ways of supporting and encouraging schools to enhance their health education programs and services. Collaboration and integration with community-wide health promotion efforts are helpful, because schools cannot do the job alone. Within the school, attempts should be made to relate all aspects of school life with the health program. Health education

needs to be sequential and developmentally appropriate. Physicians should advocate that schools have have health educators credentialed with the National Commission on Health Education (CHES) who can guide them on current methods of teaching various health content areas.

2. Physical Education and Activity

Physical education should be provided daily, with no substitutions allowed for participation in other courses or activities, and should meet national standards. There should be ample resources for the entire class in physical education so that skill building and aerobic fitness are optimized. Physical educators should be appropriately trained. Experiences should be designed to help students acquire skills and knowledge that will help them adopt and maintain physically active lifestyles and enjoy the numerous benefits of being physically active. Recess, active play during and after school, sports, and other activities should be provided as well. Emphasis should be placed on participation, not on winning. Safety should be among the educational goals of the program, with safety gear provided as appropriate.

Most pediatricians interact with physical education programs through their role in preparticipation physical examinations for sports and by providing medical cause for exemption from, and resumption of, physical activity in school. Accordingly, it is important for physicians to recognize that schools must make physical education available to all children, including those with special needs (eg, severe asthma, physical or emotional disabilities, and developmental delays), either through modifications of a regular physical education class or through an adaptive physical education program. Written excuses from medical offices that exempt children from physical education should be reserved for severe and temporary conditions, such as children on chemotherapy. When possible, pediatricians should work with the school to find an appropriate physical education curriculum for patients with chronic health conditions. If pediatricians find that school athletic departments are unwittingly discouraging some students from participating in a sport because of an overemphasis on winning as opposed to gaining physical and team-building skills, this is an opportuntiy to advocate for change.

3. Health and Mental Health Services

Historically, school health was initiated to improve health and sanitary conditions in urban schools. A recent example of school involvement in public health is the 2009 H1N1 influenza outbreak, where several school nurses played key roles in identifying the outbreak in their communities, and many public health departments used schools as sites to efficiently deliver vaccines to large numbers of children.

Today, each school district must provide students with basic first aid services, mandated health screens (eg, vision and hearing screening), immunization monitoring, and medical services that are necessary to safely accommodate a student with special medical needs in a school setting (eg, gastric tube feeding; observation and suctioning for a student with a tracheostomy; administration of medications during the school day). The school health service must also be prepared to offer immediate medical attention in crisis situations (eg, episodes of asthma or seizures, life-threatening situations affecting medically fragile children, eruption of violence, suicide, and community disasters). Trained personnel, standing policies and procedures, and key decision makers need to be identified. Most schools have ready access to emergency 911 systems.

Beyond these basic services, students often require a much broader range of health and mental health services to succeed in school. The recent proliferation of school-based and school-linked health services is a direct outgrowth of educational, health, and welfare reform movements. School-based and school-linked health services develop most often in urban settings and target disadvantaged populations. Typically, private-public partnerships coordinate a wide range of human services for the children and, often, their families.

The most important health service a school can provide is to identify student health problems and make appropriate referrals. The completeness and effectiveness of problem identification and solutions depend to a large degree on the numbers and quality of school health personnel. The more trained and sophisticated the personnel are, the more they can be expected to achieve. Differentiated staffing with appropriate use of aides, nurses, nurse practitioners, and physician consultant backup is likely to be the most cost-effective way of responding to the identified needs of a population. Students who make frequent visits to the school health room, underachieving students, or students with frequent problem behaviors are among those who may need attention.

For school health programs to be effective, linkages must be formed between the school and the source of primary health care for the child. All pediatricians can potentially benefit from the ability to link their primary care services to schools for treatment of minor conditions, follow-up and screening, medication administration, immunization delivery systems, monitoring of school absenteeism, and monitoring of achievement for selected patients. Major difficulties arise when no regular source of care or insurance coverage exists. Primary care physicians should examine ways to use school-based personnel to provide cost-effective services at school sites when it is deemed desirable for a given community. Although a school-based clinic could become a medical home for a family without other resources in a community, it is preferable to develop additional resources so that each family has an ongoing medical home that would be available over the long term. All school-based services should be linked to 24-hour, 7-days-per-week backup resources that extend beyond the school day and the school year. Providers of managed care need to examine the potential benefits of linking health services and education to families through schools. Public schools are obliged to meet the health needs of students in school if they have chronic health conditions and when health accommodations are necessary to allow these students to fully access their education. (This is outlined in Section 504 of the Rehabilitation Act of 1973.)

4. Nutrition and Food Services

Schools should provide foods prepared according to specifications that guarantee its safety, composed of competitively priced selections that are low in fat and simple sugars, and served in an appetizing way that appeals to their ethnic student populations. Foods should never be used as a reward or punishment in school. This does occur, with staff providing a pizza party for a classroom that completed an assignment, for example. The National School Meal Program, sponsored by the United States Department of Agriculture (USDA), provides free or reduced-cost lunches to low-income students and is available in most public schools. In some schools, breakfasts and snacks are also provided under the program. Some districts, recognizing that many families rely on these programs to prevent child hunger, should be encouraged to arrange for summer meal programs or collaborate with food banks and other community-based organizations during weekends and holidays. The standards for foods that fall under the national lunch program are clearly delineated. Unfortunately, many students who are eligible for these meals do not eat them for various reasons (eg, long cafeteria lines, stigmatization, and preference for items sold at schools to compete with subsidized foods). Foods sold in school canteens, vending machines, and other venues can constitute healthy nutritional choices, but many schools earn a profit from sales of high-fat snacks and carbonated high-sugar soft drinks. Colorful packaging and prominent displays of unhealthy foods can distract students from healthier choices.

In addition to educating patients and their parents, pediatricians can advocate on behalf of school-aged children. In 2004, when the federal government reauthorized the child nutrition program (which covers the national school lunch program, the Special Supplemental Nutrition Program for Women, Infants, and Children [WIC], and others), the revised public law included a clause requiring each school or school district with these programs to develop a local wellness policy that addresses childhood obesity. Schools must comply with this law if they participate in these federal school lunch or breakfast programs. They must set goals (and take action to meet goals) for nutrition education, physical activity, and other school-based activities that promote student wellness. Schools must involve a broad group of community members to set goals and oversee efforts to meet these goals, often in the form of a school health council (also referred to as a school wellness council). Pediatricians can make excellent reference sources and enthusiastic advocates for these councils. Policies of the AAP (for example, on soft drinks in schools) can provide helpful guidance.

5. Physical Environment and Transportation

Heating, ventilation, and air conditioning systems can easily fall into disrepair when funds are not set aside for adequate maintenance personnel or supplies. Health ramifications occur, but are not always obvious to students or their parents. Accumulation of mold and dust, attraction of vermin (cockroaches, rodents), and decaying organic materials can be causes of health hazards that first affect those with specific allergies, but eventually cause health problems for a broad population of students and staff. To protect the school environment, schools should use integrated pest management strategies when they remediate pest problems. These are well described by the US Environmental Protection Agency. It is important for pediatricians to be aware of the general condition of schools in their area and to look for patterns of avoidable illness or symptoms. Also related to the physical environment are those safety precautions that schools must take in designated play areas (eg, for recess) and in classes for science, physical education, and industrial arts. Traffic safety around schools (sidewalks, crosswalks, traffic lights, and monitored intersections), availability of racks to lock bicycles, and places at school to store helmets and other safety gear might seem on the surface to be important primarily for student safety; however, these factors are equally important for encouraging children to be more physically active, because they remove barriers to students' walking and riding to and from school.

6. Social Environment

Physicians must realize that patients who experience home or community violence, poverty, and hunger not only have difficulty with their own focus on education, but may change the social climate of their schools because of their experiences. Schools must have violence prevention strategies, suicide prevention strategies, actions against bullying, and policies on student discipline. Clearly written and well-known rules can contribute to a social environment that makes staff and students feel safe. Teaching staff must learn to recognize signs of student distress and know how to direct affected children to staff resources within the school (eg, a school counselor, psychologist, nurse, or site administrator trained for that purpose), who, in turn, must feel comfortable with initial assessment and working with pediatricians. Teachers should be as knowledgeable as possible about principles of child development. Teaching strategies need to be matched to the developmental and cognitive capabilities of children. Research has shown that systems that espouse noncoercive discipline and high academic expectations have the best educational outcomes.

There is always potential for spillover of neighborhood violence onto school campuses. Students who carry a weapon, possess an illicit drug, or threaten violence typically fall under a school's "zero-tolerance" rule, and are promptly suspended or expelled. If schools do not routinely involve or inform students' physicians about their suspensions or expulsions, members of the health community cannot advocate for change. Often, aberrant behaviors have health ramifications and/or health etiologies. However, many of these students with behavioral issues have unrecognized health, mental health, or family-dynamic problems that not only underlie their school behavior but are amenable to therapeutic interventions. School policies must be geared towards correcting problems, not solely towards punishing students.

Drug screening for students who want to enroll in extracurricular activities (eg, chess club, football team) became legal with a US Supreme Court decision in

2002. Although screening policies may be well intended, school districts and pediatricians must consider the ramifications of such screening. Will screening discourage students from joining extracurricular activities if they have experimented with illicit substances? Can this lead to fewer healthy connections to school and thus exacerbate rather than ameliorate substance abuse? Is there a physician with expertise in limitations of drug testing supervising any school drug testing program? Has any research found screening to be a deterrent? Has screening changed the social atmosphere of a school, and if so, for better or worse? Are false-positive results possible, and if so, what will the effect of a false-positive result be on the student and family until it is demonstrated to be false? As with any proposed screening program performed in the school setting (eg, vision screening, cholesterol screening), clear benefits of the screen must be established, and most importantly, potential harm must be known and measured against potential benefits.

7. Health Promotion for Staff

Employees' mental health and physical health are integrated with student health. School employees who exercise often and eat well are more likely to enthusiastically encourage others to do so, including their students. Employees who have taken advantage of wellness programs offered through their school district's insurance or a workplace program (eg, smoking cessation, stress management) may be more likely to recognize the importance of a healthy lifestyle for students.

8. Family and Community Involvement

Success in achieving school health goals depends largely on how well these goals are communicated with and endorsed by parents, physicians, and health and social agencies in the school's communities.

Pediatric primary and secondary care providers need to take an active role in the development and implementation of school policies. Busy pediatricians can do so by annually asking the school-aged patient (and then documenting in the patient's record) the name of the child's school. This allows for interaction, should it become necessary. Eliciting patient histories from parents and patients, as well as from school personnel, is essential particularly when there is a behavioral problem or a learning problem. This is important because children may act differently at home and at school (itself an important piece of diagnostic information), because parents may have a perspective different from other adults in the child's life, and because schools often need to become part of a management plan. Pediatricians and specialists often need to interact with schools on behalf of children with special health care or learning needs. The pediatrician may be effective not only as an advocate for a particular patient, but also for better school policies and practices that affect all students in that community.

Integrated service systems are essentially "one-stop shopping" for resources. They are also known in some communities as "family resource centers." Successful models in many communities have streamlined services and made social, health, and family support services more cost effective and user friendly. Often these services are placed in or near a school and include multiple human services in a single, easily accessible place. Health services often rank high among perceived needs in these systems.

KNOWLEDGE REQUIRED FOR PATIENT ADVOCACY AND CONSULTATION TO SCHOOLS

Many large school districts have district physicians. These are typically pediatricians, family doctors, and specialists in adolescent medicine. Districts may also employ nurse practitioners to work with these physicians. In some states, such as Maine, school districts are mandated to have such consultants. It takes time for physicians to acquire experience that is pertinent to schools. It takes repeated interaction before physicians learn to perform these tasks well and attain a consistently high quality of service delivery. In the best of these arrangements, physicians provide numerous services that, over time, become indispensable and cost-saving to schools.

The role of the school physician includes communicating on behalf of the school or school district to students' own physicians when the schools need information and assistance to address complex health and safety problems. School physicians should help schools facilitate ongoing communication between the school health office and physicians, assist schools with development and interpretation of school health-related policies (eg, exclusion policies for illness, nutrition policies), be on call for school nurses who have questions, and design and update protocols for medical procedures delivered in school (eg, gastric-tube feeding, administration of rectal diazepam).

Pediatricians may also serve as directors of comprehensive school-based or school-linked health programs. In these roles, they should have experience in planning, managing, and evaluating systems of care; be knowledgeable about funding and programmatic requirements in both health and education; and be able to establish quality assurance programs. These skills will build on a solid clinical expertise in child and youth health issues, as will firsthand knowledge and expertise with schools and educational systems. Guidelines for physicians as school consultants have been suggested (Table 23-1). Box 23-1, Box 23-2, and Box 23-3 illustrate examples of activities and suggested guidelines and approaches to be used by primary or secondary health care providers interested in working with local schools.

To assume any role in a school, a physician requires knowledge of the educational system and laws that protect students' rights in the health system. In the United States, the Individuals with Disabilities Education Act (IDEA) addresses children with special educational needs. Often, there are health needs associated with special education (eg, children with cerebral palsy often have severe developmental delay). A girl with a chronic illness, such as cancer, may not be able to learn to the extent of her full ability if she is expected to learn within the schedule of regular classroom instruction. These are examples of how

Table 23-1 Examples of a Physician's Role in Schools

CLINICAL ISSUE OR PROBLEM	EXAMPLES OF PHYSICIAN'S ACTIVITIES AS CHILD'S PRIMARY CARE PROVIDER	EXAMPLES OF PHYSICIAN'S ACTIVITIES AS CONSULTANT TO SCHOOL OR SCHOOL SYSTEM
Learning disability	1. Requests teacher's account of child's learning and behavior, as well as results of individualized testing 2. Shares results of medical evaluation of child with the school 3. Works cooperatively with school personnel and parents to develop educational and behavioral management plan for child (may include school visit) 4. Sets up mechanism for follow-up on behavioral and educational progress of child	1. Serves on district committee to accomplish biannual review of progress of students with disabilities 2. Assists in setting up mechanism for providing follow-up behavioral and academic information to physicians who have placed students on psychoactive medication 3. Provides in-service session for classroom teachers on new concepts in attention-deficit/hyperctivity disorder 4. Advises school board on need for movement training for children who have learning disabilities
Asthma (school-age)	1. Requests school information on absenteeism, communicates with school nurse; obtains evidence of nonparticipation in physical education activities 2. Sets up mechanism for regular administration of bronchodilator at school 3. Sets up follow-up mechanism for continued monitoring of school attendance, medication-taking compliance, and participation in appropriate physical activities	1. Reviews absenteeism data to identify groups of students who have excessive absences that might be amenable to some intervention 2. Assists curriculum director and nurse in developing educational programs for children who have asthma 3. Helps publicize program and communicates directly with students; solicits primary care physicians' input and support for the educational program by reinforcing concepts in their patient visits

Adapted from Nader P. A pediatrician's primer for school health activities. *Pediatr Rev.* 1982:4:82–92.

BOX 23-1 Guidelines for the Physician as Child's Primary Care Provider

1. Always obtain permission from the parents to communicate with the school, and keep them informed of their child's progress.
2. Approach all school personnel as co-professionals who have skills and interests that complement your expertise and who can provide you with information you do not have. Recognize their interest in helping the children in their charge.
3. When contacting a school for the first time, contact the principal initially.
4. When calling a teacher, find out the best time for the teacher to talk.
5. Encourage direct school-parent and parent-school communication.
6. Be willing to attend a school meeting, if necessary, to share information and develop treatment plans.
7. Listen carefully to ascertain the school personnel's main concerns and questions, and attempt to respond to them.

BOX 23-2 Guidelines for the Physician as School Health Consultant

1. Distinguish between the roles of a primary care provider and those of a school consultant.
2. Become aware of laws and regulations affecting schools, including those related to school finance, education for children with disabilities, bilingual education, and other educational mandates.
3. Become knowledgeable about the formal and informal decision-making processes in schools regarding regular and special education of children (including health education).
4. Be a liaison to the rest of the medical community.
5. Establish a contract with the school that defines mutually agreed-on expectations and objectives.
6. Provide a regular report on your consultation to the school district.
7. Attempt to establish relationships at all levels and departments of the school system to permit access from the board and superintendent level to that of the classroom teacher.
8. Become aware of group process dynamics and decision making in groups.

BOX 23-3 A Checklist for Working With Schools

STATE POLICIES AND PROGRAMS

- Have you familiarized yourself with state policies and programs related to comprehensive school health programs?
- Have you checked to see whether health outcome objectives exist, and, if so, how they are assessed?

LOCAL POLICIES AND PROGRAMS

- Have you familiarized yourself with district policies and programs related to comprehensive school health programs?
- Have you determined what health curriculum, textbooks, and materials are actually being used in the schools?
- Have you ascertained the following parameters?
  - Policies and programs that need strengthening
  - Serious gaps or deficits
  - Opportunities for health professionals to contribute meaningfully

INFLUENCING LOCAL POLICIES AND PROGRAMS

- Do you know how the local education system works? Who makes decisions? Who has authority? Who actually does the work?
- Do you know who supports (and who is concerned with) various aspects of comprehensive school health programs and their reasons for doing so?
- Have you contacted appropriate officials about your ideas and obtained their support for working with schools?
- Have you refined your ideas in consultation with key parties—teachers, administrators, school health professionals, public health professionals, school board members, and parents?
- Have you provided for periodic progress reports and changed direction or emphasis based on their results?

From National Association of State Boards of Education. *How Schools Work and How to Work With Schools.* Alexandria, VA: The Association; 1989.

health problems may affect the need for special education services. The school must address both the educational and the health needs in the child's written individualized education program (IEP). Laws require schools to place students in the least restrictive environment. Sometimes this means bringing in 1:1 nurse coverage in the classroom for a student (eg, when the child is tracheostomy dependent and requires frequent suctioning and continuous observation). In other circumstances, a child's specialized health needs require training of non-health staff who are already in the school or classroom. It is important for physicians to describe the child's health need (eg, "my patient needs someone trained to recognize a seizure, record the incident, and administer rectal diazepam if the seizure lasts longer than 5 minutes") and refrain from prescribing how the school should meet this need (eg, avoid saying "my patient needs a full-time 5-day-a-week nurse" or "my patient needs a 1:1 aid"). Schools need to be able to choose from an assortment of safe solutions. Working with the school in a cooperative manner is the best way to meet the student's needs without compromising the student's safety and without unnecessarily compromising the school's budget.

Section 504 of the Rehabilitation Act of 1973 is another law with which physicians must be familiar. To receive special services under Section 504, a student does not need to have any special learning need. Schools must provide any service within reason if that service is required to safely accommodate a student's disabling condition. When there is more than 1 possible way to accommodate a student's educational needs, schools are permitted to make that choice. Unlike IDEA laws addressing special education, disabling conditions under Section 504 can be purely medical or physical, and are not required to include a problem that affects learning. However, the condition must be severe enough to "substantially limit a major life activity." A concrete example of an accommodation that a school must make is to build a ramp if necessary to accommodate a student with muscular dystrophy who is confined to a wheelchair. But Section 504 also applies to less concrete forms of access to education. Consider the example of a young student with type 1 diabetes who requires someone trained to assist him in testing and interpreting his serum glucose levels during the school day. Without this service, the student could not safely access his education. A "504 plan" is an individualized plan that describes what the school will do for a specific student to ensure access to the student's education. It describes the actions a school will take to override the substantial limitation in a student's major life activity. In this example, the district may relocate this child to a nearby school that has a 5-day-a-week nurse. Alternatively, the district may choose to keep the child in the originally assigned school and teach lay staff members to recognize hypoglycemia and respond to it (ie, test blood sugar, administer oral sucrose, and even inject glucagon). The district can arrange for a licensed nurse to come to the school each day at lunch hour to administer insulin. Many students may require medications, including psychoactive drugs, to keep them in school and "on task," but most will not require a 504 plan. The physician must master ways to ensure medication compliance in school. Standardized procedures for medication administration in schools are available.

It is advisable for a pediatrician to refrain from prescribing special services for a patient after having communicated with only the student and parent. Too often, parents encourage doctors to write notes to schools, often scribbled on prescription pads, that demand that a school provide a student with "door-to-door transportation," or an "air-conditioned classroom for heat intolerance," when these services are convenient but not medically necessary. Interaction with a school representative (eg, a school nurse or principal) can help the physician find an appropriate intervention without unnecessarily taxing the school budget and jeopardizing other worthwhile school programs. For more information on these laws, the US Department of Education Web site provides

continuously updated resources. For IDEA, go to www.ed.gov/offices/OSERS/Policy/IDEA/index.html. For Section 504, go to www.ed.gov/about/offices/list/ocr/504faq.html.

NEIGHBORHOODS: WHATEVER IT TAKES

Schools need to work together with other neighborhood groups and institutions to support the optimal growth of children. In the early 1990s, Geoffrey Canada started the Harlem Children's Zone, a nonprofit organization for poverty-stricken children and families living in Harlem, NY. The 2 fundamental principles of the organization were to help children as early in their lives as possible and to create a critical mass of adults around them who understand what it takes to help children succeed. Described in the book *Whatever It Takes,* by Paul Tough, the Harlem Children's Zone provides free support for the children and families in the form of parenting workshops; a preschool program; public charter schools; health clinics and community centers for children and adults during after-school, weekend, and summer hours; youth violence prevention efforts; and social services, such as a foster-care prevention service. The organization's goal is to break the cycle of generational poverty for the thousands of children and families it serves, and to keep children on track through college and into the job market.

In 2010, the Obama administration authorized the establishment of 20 "Promise Neighborhoods" to be modeled after the Harlem Children's Zone, aimed at providing this full network of services to entire neighborhoods from birth to college to career. Promise Neighborhoods, established under the legislative authority of the Fund for the Improvement of Education Program, will provide funding to support eligible entities, including nonprofit organizations, which may include faith-based nonprofit organizations and institutions of higher education.

CONCLUSION

It is important for pediatricians to be aware of and involved in all aspects of the community in which children are growing. Most importantly, pediatricians can help school health programs ensure a safe, healthy, and nurturing environment for the children they serve. Schools are a logical place to identify children in need of health and mental health referrals, as well as a good environment in which to provide preventive health care and education. Pediatricians who become integral parts of these systems can play a major role in improving health and educational outcomes for children in their communities.

TOOLS FOR PRACTICE

Community Advocacy and Coordination

- *Adolescent & School Health* (Web page), Centers for Disease Control and Prevention (www.cdc.gov/healthyyouth/schoolhealth/index.htm)
- *Building the Legacy: IDEA 2004* (Web page), US Department of Education (idea.ed.gov)
- *Connected Kids Clinical Guide* (booklet), American Academy of Pediatrics (www2.aap.org/connectedkids/ClinicalGuide.pdf)
- *Health, Mental Health and Safety Guidelines for Schools* (Web site), American Academy of Pediatrics (www.nationalguidelines.org)
- *NACCHO Toolbox* (Web page), National Association of County and City Health Officials (www.naccho.org/toolbox)
- *The National School Lunch Program (NSLP)* (Web page), US Department of Agriculture (www.fns.usda.gov/nslp/national-school-lunch-program-nslp)
- *State School and Health Resources* (Web page), American Academy of Pediatrics (www2.aap.org/sections/schoolhealth/contactmap/section_contacts.cfm.htm)

Engaging Patient and Family

- *Frequently Asked Questions About Section 504 and the Education of Children With Disabilities* (fact sheet), US Department of Education (www.ed.gov/about/offices/list/ocr/504faq.html)

Practice Management

- *Frequently Asked Questions About Section 504 and the Education of Children with Disabilities* (fact sheet), US Department of Education (www.ed.gov/about/offices/list/ocr/504faq.html)
- *Building the Legacy: IDEA 2004* (Web page), US Department of Education (idea.ed.gov)

AAP POLICY

American Academy of Pediatrics Committee on Children With Disabilities. The pediatrician's role in development and implementation of an individual education plan (IEP) and/or an individual family service plan (IFSP). *Pediatrics*. 1999;104(1):124–127 (pediatrics.aappublications.org/content/104/1/124)

American Academy of Pediatrics Committee on Injury, Violence, and Poison Prevention and Council on School Health. School transportation safety. *Pediatrics*. 2007;120(1):213–220. Reaffirmed October 2011 (pediatrics.aappublications.org/content/120/1/213)

American Academy of Pediatrics Committee on School Health. Policy Statement—Guidance for the administration of medication in school. *Pediatrics*. 2009;124(4):1244–1251. Reaffirmed February 2013 (pediatrics.aappublications.org/content/124/4/1244)

American Academy of Pediatrics Council on School Health. Out-of-school suspension and expulsion. *Pediatrics*. 2013;131:(3):e1000–e1007 (pediatrics.aappublications.org/content/131/3/e1000)

American Academy of Pediatrics Committee on School Health. School-based mental health services. *Pediatrics*. 2004;113(6):1839–1845. Reaffirmed May 2009 (pediatrics.aappublications.org/content/113/6/1839)

American Academy of Pediatrics Council on School Health. School-based health centers and pediatric practice. *Pediatrics*. 2012;129(2)387–393 (pediatrics.aappublications.org/content/129/2/387)

American Academy of Pediatrics Council on School Health and Committee on Nutrition. Snacks, sweetened beverages, added sugars, and schools. *Pediatrics*. 2015;135(3)575–583 (pediatrics.aappublications.org/content/135/3/575)

American Academy of Pediatrics Council on School Health. Medical emergenices occurring at school. *Pediatrics*.

2008;122(4):887–894. Reaffirmed September 2011 (pediatrics.aappublications.org/content/122/4/887)
American Academy of Pediatrics Council on School Health. Role of the school nurse in providing school health services. *Pediatrics*. 2008;121(50):1052–1056 (pediatrics.aappublications.org/content/121/5/1052)
American Academy of Pediatrics Council on School Health. The crucial role of recess in school. *Pediatrics*. 2013; 131(1)183–188 (pediatrics.aappublications.org/content/131/1/183)
American Academy of Pediatrics Council on School Health. Role of the school physician. *Pediatrics*. 2013;131(1) 178–182 (pediatrics.aappublications.org/content/131/1/178)
American Academy of Pediatrics Council on School Health and Committee on Substance Abuse. The role of schools in combating illicit substance abuse. *Pediatrics*.2007; 120(6):1379–1384 (pediatrics.aappublications.org/content/120/6/1379)

Chapter 24

PROMOTING THE HEALTH OF ADOLESCENTS

Breena Welch Holmes, MD; Paula M. Duncan, MD

INTRODUCTION

Adolescence presents unique challenges for health promotion in communities. To promote healthy outcomes for youth and deliver high-quality preventive and treatment services for adolescents, pediatricians must work with community organizations and service providers in a community-based system of care. The role of families and schools as the primary community of children is discussed in Chapter 14, Pediatric History: Assessing the Social Environment. As adolescents develop autonomy and explore new behaviors, they become involved in the larger community.

FRAMEWORKS FOR HEALTHY ADOLESCENT DEVELOPMENT

Protective factors are individual or environmental characteristics, conditions, or behaviors that reduce the effects of stressful life events, increase an individual's ability to avoid risks or hazards, and promote social and emotional competence to thrive in all aspects of life now and in the future. One of these factors is resilience, the ability to cope with and adapt to change. Being resilient allows children and youth to overcome difficulties in their lives.

In the 1990s, researchers developed a framework of developmental assets—the strengths and resources that promote positive development in adolescents as they transition from childhood. The Search Institute, a social science research group, identified 40 positive factors that promote healthy development in young people. A greater number of assets in the lives of adolescents correlates with fewer risk-taking behaviors.

Pediatricians can have a positive effect on youth development by helping to create opportunities for all youth to feel connected, learn to make good decisions, help others, and develop skills such as managing stress and taking responsibility for their own behaviors. The components of healthy adolescent development can be characterized according to 3 prominent frameworks: developmental tasks, Circle of Courage, and the Seven Cs.

Developmental Tasks

Bright Futures, the 2008 Preventive Services Guidelines, adopted the Association of Maternal and Child Health Programs framework to describe the 7 developmental tasks of adolescence (Box 24-1).

Circle of Courage

Another way to describe the opportunities youth need to thrive is the Circle of Courage, a framework used by Brendtro and colleagues, who identified generosity, independent decision making, mastery, and belonging as essential to a healthy adolescence. Ideally, the activities adolescents pursue at the community level would provide opportunities to develop these qualities.

Seven Cs

Lerner and Pittman's work has identified 5 Cs (competence, connection, contribution, character, and confidence) as key components of a positive youth development framework, and Lerner tested them through his 4H study work. Based on his work with youth, Ginsburg has added coping and control to the original five.

In his book *Reaching Teens,* Ginsburg describes a strengths-based approach and core priniciple. He also describes "wisdom from model" strengths-based programs that work with youth who are traditionally labeled "at risk."

Approaches for Assessing the Adolescent Environment

Youth need opportunities to grow in each of the areas outlined above (eg, opportunities to help others, practice independent decision making, and establish

BOX 24-1 Seven Developmental Tasks of Adolescence

- Healthy behaviors
- Caring and supportive relationships
- Physical, cognitive, emotional, social, and moral competencies
- Self-confidence, hopefulness, and well-being
- Resilience when confronted with life stressors
- Responsible and independent decision making
- Positive engagement in the life of the community

From Hagan JF, Shaw JS, Duncan P. *Bright Futures Guidelines for Health Supervision of Infants, Childrens, and Adolescents*. 3rd ed. Elk Grove Village, IL: American Academy of Pediatrics; 2008 and Fine A, Large R. *A Conceptual Framework for Adolescent Health: A Collaborative Project of the Association of Maternal and Child Health Programs and the State Adolescent Health Coordinators Network*. Washington, DC: Association of Maternal and Child Health Programs; 2005.

relationships with peers). Families often provide a setting for this growth and development, but by adolescence, school activities, community organizations, faith-based groups, and sports teams often supply youth with development opportunities. The inventory in Box 24-2 can help pediatricians assess their community's programs and services for adolescents.

Pediatricians who work toward positive youth development in their communities should also be familiar with the information in Table 24-1.

Klein and colleagues have identified and tested an inventory tool for use by community organizations for assessment and implementation of the positive youth development approach.

Kretzmann and McKnight have also developed a framework for use at the community level.

BOX 24-2 Strengths-Based Practices Inventory

- Does the program help adolescents feel respected, valued, and treated as if they are knowledgeable and capable?
- Does the program help adolescents and families to acquire knowledge, skills, and self-confidence to do things for themselves?
- Does the program focus on helping adolescents and families develop positive relationships within their own lives?

Derived from Green BL, McAllister CL, Tarte JM. The Strengths-Based Practices Inventory: a tool for measuring strengths-based service delivery in early childhood and family support programs. *Families in Society: The Journal of Contemporary Social Services*. 2004;85(3):326–334.

Table 24-1 Features of Community-Based Positive Developmental Settings

FEATURE	DESCRIPTORS	OPPOSITE POLES
Physical and psychological safety	Safe and health-promoting facilities and practices that increase safe peer group interaction and decrease unsafe or confrontational peer interactions.	Physical and health dangers; fear; feelings of insecurity; sexual and physical harassment; verbal abuse.
Appropriate structure	Limit setting; clear and consistent rules and expectations; firm enough control; continuity and predictability; clear boundaries; age-appropriate monitoring.	Chaotic; disorganized; laissez-faire; rigid; overcontrolled; autocratic.
Supportive relationships	Warmth; closeness; connectedness; good communication; caring; support; guidance; secure attachment; responsiveness.	Cold; distant; overcontrolling; ambiguous support; untrustworthy; focused on winning; inattentive; unresponsive; rejecting.
Opportunities to belong	Opportunities for meaningful inclusion, regardless of one's gender, ethnicity, sexual orientation, or disabilities; social inclusion, social engagement, and integration; opportunities for sociocultural identity formation; support for cultural and bicultural competence.	Exclusion; marginalization; intergroup conflict.
Positive social norms	Rules of behavior; expectations; injunctions; ways of doing things; values and morals; obligations for service.	Normlessness; anomie; laissez-faire practices; antisocial and amoral norms; norms that encourage violence; reckless behavior; consumerism; poor health practices; conformity.
Support for efficacy and mattering	Youth based; empowerment practices that support autonomy; making a real difference in one's community; being taken seriously. Practices that include enabling, responsibility granting, and meaningful challenge. Practices that focus on improvement rather than on relative current performance levels.	Unchallenging; overcontrolling; disempowering; disabling. Practices that undermine motivation and desire to learn, such as excessive focus on current relative performance level rather than improvement.
Opportunities for skill building	Opportunities to learn physical, intellectual, psychological, emotional, and social skills; exposure to intentional learning experiences; opportunities to learn cultural literacies, media literacy, communication skills, and good habits of mind; preparation for adult employment; opportunities to develop social and cultural capital.	Communities that promote bad physical habits and habits of mind; practices that undermine school and learning.
Integration of family, school, and community efforts	Concordance; coordination; synergy among family, school, and community.	Discordance; lack of communication; conflict.

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POSITIVE YOUTH DEVELOPMENT FOCUS

As part of their preventive services visits with adolescents, pediatricians identify individual patient strengths through developmental surveillance, give feedback about progress on the developmental tasks to youth and (if appropriate) their parents, and practice shared decision making when a change needs to be made. As community pediatricians, they play an additional role. Based on their roles as board members, team physicians, volunteer coaches, community health leaders, and parents, pediatricians provide consultation about using the positive youth development approach and advocating for this approach with funders. Pediatricians understand the importance of community partners in the lives of adolescents. These partners may include state and national organizations of the American Academy of Pediatrics (AAP), state health departments, schools, faith-based organizations, and community organizations like 4H and Boys and Girls Clubs of America. Pediatricians can advocate for programs that have demonstrated effectiveness by being aware of what programs work for promoting healthy adolescent development. For example, Lerner has reported that participants in 4H, when compared to youth in other out-of-school programs, had better outcomes in healthy behaviors, academic competence, school engagement, and community contribution. The Big Brother/Big Sister mentoring programs evaluation in 2013 has found improved social acceptance among participants compared with those youth who have not yet been matched with a mentor. When followed over time, participants also showed improvement or maintenance of scholastic competence, educational expectations, attitudes toward risky behavior, and parental trust. Opportunities for community service are also associated with risk reduction in youth, and for this reason the Community Preventive Services Task Force of the Substance Abuse and Mental Health Services Administration recommends youth development–focused behavioral interventions coordinated with community service.

In recent years, many youth advocacy organizations have become more aware of, and focused on, positive youth development strategies.

In addition, pediatric practices often have a staff person who is in charge of knowledge about and links to community resources. Among these resources are programs with a youth development focus or proven efficacy for easy referral of patients seen for preventive services and acute visits in the medical home.

RISK REDUCTION FOCUS

Health promotion activities at the community level also focus on the prevention of the 6 risk behaviors that result in the greatest morbidity and mortality for adolescents and adults: unhealthy nutrition, inadequate physical activity, unhealthy sexual behaviors, substance use and abuse, unintentional injury-related behavior, and intentional injury-related behaviors.

In some situations, physicians provide health promotion consultation and advocacy about specific risk areas. This can result from personal interest or expertise on the part of the physician or in response to a critical need identified among the patient population or in the community (eg, prescription drug abuse or teen suicide).

Recent research has identified several community-based strategies for adolescent risk reduction. Safe, supervised recreational activities and physical activity promote healthy development. Neighborhoods and communities can work together with pediatricians to improve the built environment. Researchers have shown that increasing the percentage of park space in a neighborhood increases the percentage of non-overweight 8- to 12-year-olds.

Schools and retail environments that support healthy choices are especially important to adolescents' decision making regarding nutrition, tobacco, and alcohol. Pediatricians can advocate for laws to regulate the marketing and sale of non-nutritious food, tobacco, and alcohol to adolescents. They can also advocate at the community level for oral health initiatives like water fluoridation, access to dental homes, and school-based programs for screening and referral. Pediatricians can partner with communities and public health departments to call attention to the importance of adolescent vaccines in promoting healthy communities, and can conduct information campaigns to improve awareness. This is becoming more important with increasing rates of vaccine refusal.

Communities can also promote healthy attitudes about sexuality. Accepting one's changing body and exploring sexual feelings and identity are among the developmental tasks of adolescence. Pediatricians should advocate for medically accurate sexuality education in schools, and for an emotionally and physically safe environment for youth who are gay, lesbian, bisexual, or transgender. The Centers for Disease Control and Prevention Task Force on Community Preventive Services has identifed competence, improved decision making, self-determination, and improved communication skills as critical components in a recommended sexuality risk reduction program.

Community-based substance abuse prevention is most effective when it involves programs to help individuals develop skills along with policies that support healthy behaviors. Communities must make enforcement of these policies a high priority.

An emotionally and physically safe environment is also critical to healthy adolescent development. School programs about bullying and Internet safety can contribute to a community-wide effort to promote a positive climate. Injury prevention at the community level might include safe driving legislation and enforcement, seatbelt and bike helmet legislation, and gun violence prevention.

Pediatricians are ideal advocates for wellness and mental health support for adolescents and should encourage opportunities for strength-building activities. Nutrition, exercise, sleep, sunshine, reading, music, sports, and spirituality all contribute to an adolescent's sense of well-being. These factors are essential components of a strategy to promote mental health. Communities also need ongoing resource development to help adolescents in crisis, those experiencing problems in school, and those in need of mental health treatment.

Schools continue to play a vital role in adolescents' community connections. As discussed in Chapter 23, Promoting the Health of School-Aged Children, coordinated school health has 8 essential components: health education and services, counseling, psychological and social services, physical education, nutrition services, healthy school environment (which includes emotional safety), health promotion for staff, and family/community involvement. Pediatricians should be a part of a coordinated school health program and, ideally, participate in school activities related to this approach.

Media can have significant effects on adolescent health behavior choices. Opportunities for education about safe, effective, and healthy media use should be promoted by families, schools, physicians, and community organizations.

Finally, pediatricians are a valuable source of support for parents and guardians, who may benefit from an understanding of strengths and positive youth development. Building on relationships often forged when children were much younger, the medical home provides adolescents and their families a supportive extension of the community. A helpful resource for parents is the AAP publication *Building Resilience in Children and Teens*.

Kenneth R. Ginsburg's book *Reaching Teens* is an excellent guide to implementation of the strengths-based approach for health care professionals, social workers, educators, and all professionals who work in youth-serving organizations.

ADOLESCENTS IN DIFFICULT CIRCUMSTANCES

Pediatricians should recognize the special needs of certain groups within a community and strive to create opportunities for these vulnerable young people. Adolescents with special health care needs and vulnerable families who, because of income level or geography, lack access to social, cultural, and economic resources should be supported by pediatricians, public health professionals, and community organizations. Additional special populations include youth in foster care (see Chapter 72, Children in Foster or Kinship Care), youth in the judicial system (see Chapter 73, Children in the Juvenile Justice System), youth with previous loss or trauma (see Chapter 68, Children Exposed to Adverse Childhood Experiences), youth whose parents are in the military (see Chapter 77, Children in Military Families), youth with special educational needs, adolescents who are parents, and youth with substance abuse problems.

CONCLUSION

Pediatricians play a vital role in ensuring that their communities support the developmental tasks of adolescence. *Bright Futures* provides specific guidance to assist health care professionals in this area: Box 24-3 identifies specific recommendations.

A comprehensive, coordinated approach promotes healthy outcomes in adolescents. Pediatricians are an essential component of this cooperative effort. Health promotion for adolescents involves the medical home, community-based organizations, schools, parents and guardians, and the youth themselves. By helping to develop strengths-based programs and foster the growth of developmental assets, pediatricians can encourage positive adolescent development.

BOX 24-3 Recommendations for Promoting Community Relationships and Resources

- Learn about the community and collaborate with community partners (know your local resources, schools, and public health officials)
- Recognize the special needs of certain groups and collaborate with social services
- Encourage informal support: parent support networks
- Consult and advocate: opportunities to become agents for health-promoting community change

Derived from Hagan JF, Shaw JS, Duncan P. *Bright Futures Guidelines for Health Supervision of Infants, Children, and Adolescents*. 3rd ed. Elk Grove Village, IL: American Academy of Pediatrics; 2008.

TOOLS FOR PRACTICE

Community Advocacy and Coordination

- *Building the Legacy: IDEA 2004* (Web page), US Department of Education (idea.ed.gov)
- *Adolescent and School Health* (Web page), Centers for Disease Control and Prevention (www.cdc.gov/healthyyouth/schoolhealth/index.htm)
- *State School and Health Resources* (Web page), American Academy of Pediatrics (www2.aap.org/sections/schoolhealth/contactmap/section_contacts.cfm.htm)
- *Healthy People 2020 Evidence-Based Resources* (Web page), Office of Disease Prevention and Health Promotion (www.healthypeople.gov/2020/tools-resources/Evidence-Based-Resources)
- *Healthy People 2020 Program Planning* (Web page), Office of Disease Prevention and Health Promotion (www.healthypeople.gov/2020/tools-and-resources/Program-Planning)
- *Healthy People 2020 Count Data Resources* (Web page), Office of Disease Prevention and Health Promotion (www.healthypeople.gov/2020/county-data-resources)
- *National School Lunch Program (NSLP)* (Web page), US Department of Agriculture (www.fns.usda.gov/nslp/national-school-lunch-program-nslp)
- *Health, Mental Health, and Safety Guidelines for Schools* (Web site), American Academy of Pediatrics (www.nationalguidelines.org)

Engaging Patient and Family

- *Frequently Asked Questions About Section 504 and the Education of Children With Disabilities* (fact sheet), US Department of Education (www.ed.gov/about/offices/list/ocr/504faq.html)
- *National Center for Children in Poverty Data Tools* (Web page), National Center for Children in Poverty (nccp.org/tools)

AAP POLICY

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Screening

Chapter 25
SCREENING: GENERAL CONSIDERATIONS

Paul H. Dworkin, MD

Primary care physicians are well positioned to participate in the early detection of childhood problems and conditions because of their access to young children and families. Universal screening refers to the process of testing all children at certain appropriate ages to detect those at high risk for significant deviations from normal. The emphasis is on distinguishing between children at high and low risk for certain problems, rather than on diagnosing such conditions. Screening typically involves the application of rapidly administered tests, examinations, or other procedures. Screening tools or instruments may also be used for validating history or physical findings after concerns are raised.

The number of conditions for which screening is currently recommended or mandated continues to increase. Research has better delineated the adverse effects of certain childhood conditions, such as the neurobehavioral and intellectual deficits associated with low-level lead exposure and iron-deficiency anemia. The Human Genome Project and improving technologies have identified many genes that may carry mutations that cause disorders and that can be identified by simple tests. The expansion of diverse technologies that rapidly measure multiple analytes from a single blood spot allow for more effective newborn screening. Changing morbidity within pediatric practice has led to emphasis on early identification of behavioral, developmental, and psychosocial problems, along with the need for updating screening policies for certain conditions such as autism spectrum disorders.

Societal changes have influenced the scope and content of screening programs. These changes include demands for confidentiality of test results, concerns with the stigma associated with certain diagnoses, and legislative mandates requiring early intervention for children who have developmental disabilities and other chronic conditions. Remarkable advances in understanding of genetics and epigenetics have raised concerns that the ability to diagnose a genetic disorder for which no treatment is available may create undue anxiety and frustration. Health care reform, with its emphasis on population health, primary prevention, and cost containment, has contributed to an increased scrutiny of screening practices. Despite the time-honored tradition of performing screening tests during child health supervision visits, the effectiveness of many such practices is uncertain. For example, the US Preventive Services Task Force (USPSTF) issued recommendations for clinical preventive services in 2014 that endorsed universal screening for a limited number of conditions during childhood and adolescence. The Task Force recommended universal newborn screening for congenital hypothyroidism, phenylketonuria, sickle cell disease, and hearing loss; for major depressive disorder in adolescents; for obesity among 6- to 18-year-olds; and for childhood visual impairment. In contrast, they cited insufficient evidence to support universal screening for iron-deficiency anemia, blood lead levels, and lipid disorders. Because recommendations for screening practices are typically determined by a combination of limited scientific data, empiricism, and good intentions, they often provoke considerable debate.

The 2006 recommendations of the American Academy of Pediatrics (AAP) Council on Children with Disabilities endorse the administration of formal developmental screening tools at 9, 18, and 24 to 30 months of age. The statement emphasizes the importance of using such tools in the context of a comprehensive, longitudinal process of surveillance and screening that also engages parents as partners in the process of early detection, interprets the results of screening tools in the context of all that is known about the child and family, and ensures that positive screening results lead to further assessment and, if indicated, intervention.

This chapter reviews the criteria by which conditions are judged appropriate for screening and tests are selected for use in screening programs. In addition,

screening is compared with other approaches to early detection during the provision of child health supervision services.

TRADITIONAL CRITERIA FOR CONDITIONS TO BE SCREENED

Historically, disease conditions have been judged appropriate for screening if they fulfill certain well-accepted and still relevant criteria that evolved during the last century.

1. The condition must be an important health problem and have significant morbidity or mortality, with serious consequences if not detected and remediated early. For example, the adverse effects of early sensorineural hearing loss on language development and subsequent academic achievement and on social and emotional development are cited to support recommendations for universal screening for hearing impairment of all newborns.
2. The condition must be sufficiently prevalent to justify the cost of screening programs. Determining the true prevalence of certain conditions is difficult. Furthermore, rates of conditions often vary widely across different geographic regions. For example, the Centers for Disease Control and Prevention (CDC) has recommended that state or local governments formulate their own recommendations for lead screening based on local data. Such data is important in determining cost versus benefit to society. The AAP has similarly encouraged physicians to follow local screening guidelines when available.
3. The screening program should include the entire population, especially those at particular risk for the condition. Screening programs are optimally implemented within a comprehensive system of preventive child health care directed at the entire population. The lack of access of some young children and families to child health supervision services and a medical home is well recognized. Disadvantaged children at increased risk for conditions such as iron-deficiency anemia, lead poisoning, and developmental delay may be less likely to receive recommended screening tests because of their limited access to health care.
4. Adequate resources must be available for the definitive diagnosis and treatment of disorders identified by screening. The lack of adequate diagnostic and therapeutic resources for developmental, behavioral, and psychosocial problems hampers efforts at early detection and intervention. While autism screening promotes early detection of at-risk children, insufficient evaluation capacity often delays diagnosis. Universal screening for hearing impairment in infants is problematic for some individuals because follow-up diagnostic testing and treatment of hearing loss may be difficult to carry out in rural or remote areas. Screening results should inform advocacy efforts to address gaps and capacity issues.
5. The condition, after detection, must be treatable or controllable. Developmental screening is based on the premise that positive screening will result in an intervention that will benefit the child. The benefits of early intervention for children who have developmental disabilities (eg, Down syndrome, cerebral palsy) are well established. Furthermore, evidence increasingly supports the benefits of early identification and intervention for vulnerable young children who are at risk of adverse developmental and behavioral outcomes.
6. Detection and treatment during the asymptomatic phase can improve prognosis, and early treatment is advantageous. Newborn screening for inborn errors of metabolism (eg, congenital hypothyroidism, phenylketonuria) is clearly beneficial because early treatment prevents later brain damage and neurologic impairment. Similarly, prophylactic penicillin and pneumococcal conjugate vaccine have been clearly shown to reduce both morbidity and mortality from pneumococcal infections in young children who have sickle cell anemia. Screening for cystic fibrosis is supported by evidence that treatment before the development of severe pulmonary disease will increase well-being and the duration of survival.
7. The cost of screening should be outweighed by the savings in suffering and alternative expenditure that would occur if the condition were not diagnosed until the symptomatic stage. Costs of screening programs must include not only the direct cost of the procedures themselves, but also the cost of diagnostic evaluation, monitoring, and intervention as a consequence of screening, as well as the costs of false-positive and false-negative results. For example, one study found the total costs for initiating and establishing a universal newborn hearing screening program, including post-discharge screening and diagnostic evaluation costs, was $46 per infant screened when utilizing automated auditory brainstem response (AABR) and $58 when using transient evoked otoacoustic emissions (TEOAE). However, few studies have examined the long-term cost effectivenss of universal newborn hearing screening in relation to such other approaches as risk factor screening.

CRITERIA FOR SCREENING TESTS

Once the decision has been made to screen for a particular disorder, judging which tests are appropriate to use in screening programs is based on widely accepted criteria.

1. Tests must be simple, practical, convenient, and safe. The relative ease and simplicity of performing TEOAE testing facilitates universal screening for hearing impairment in infants. However, the decrease in specificity of this test during the first 24 hours of life poses logistical problems in that early discharge may necessitate a second screening on an outpatient basis. Computer scoring software is available for several developmental screening tests to assist in administration within the busy practice setting.
2. Tests must be acceptable to patients and families, with assurance of informed parental consent and confidentiality of findings. Informed parental consent includes access to information on such issues as potential false-positive and false-negative findings, the possible need for time-consuming and often expensive follow-up evaluations, and the anxiety

generated by positive screening results. Confidentiality of screening results must be maintained because positive findings for disorders such as HIV infection and sickle cell disease may be socially stigmatizing and result in discrimination by insurance companies and potential employers.

3. Tests must be accurate and reliable. The validity of screening tests consists of 2 components: sensitivity—the proportion of individuals who have a disorder whose test result is positive; and specificity—the proportion of individuals who do not have the disorder whose test is negative. Of particular clinical importance is the probability of an individual having the disorder when the test is positive—the test's positive predictive value—as well as the probability of not having the disorder when the test is negative—negative predictive value. The predictive value of a test depends greatly on the prevalence of the disorder in the population being tested. The low prevalence of hearing impairment (approximately 1 to 3 of every 1,000 otherwise healthy newborns) contributes to the relatively low specificity of TEOAE testing alone, and suggests the potential benefit of a 2-step screening approach with postive TEOAE results confirmed by AABR testing.
4. Tests should be economical. The costs of newborn screening for metabolic disorders such as congenital hypothyroidism, galactosemia, and maple syrup urine disease are minimal because such tests are incorporated within established screening programs for phenylketonuria. The cost of screening for such rare disorders in isolation would be prohibitive.
5. Appropriate specialists should be available to assist in the interpretation of screening results, as well as to facilitate diagnostic assessment and treatment. The screening program must ensure the availability of appropriate education and genetic counseling for parents.

SCREENING AS A PUBLIC HEALTH SERVICE

In recent years, the criteria for screening have evolved to include a broader definition of benefits to the affected child and the child's family, including the prevention of negative consequences or optimization of all outcomes. A greater emphasis on more moderate and family-centered benefits, including a reduction in recurrence risks through genetic counseling and the avoidance of diagnostic odysseys associated with unrecognized conditions such as uncommon inborn errors of metabolism, have implications for policy deliberations. For example, newborn screening for cystic fibrosis is justified based on such outcomes as nutritional benefits and improved growth, cognitive benefits for children at nutritional risk, reduction in diagnostic delays, the avoidance of hospitalization, and the recognition of carriers.

EVIDENCE-BASED ASSESSMENTS

Recommendations for selecting disorders for population-based screening should include the systematic assessment of evidence of effectiveness and benefits using standardized methods. The USPSTF develops recommendations for screening based on systematic reviews of research on the certainty of the evidence and on the balance of benefits and harms of the proposed screening process. The USPSTF currently grades its recommendations according to both the certainty and the magnitude of net benefit, judging each as either Substantial, Moderate, Small, or Zero/negative. For example, if screening for a given condition is found to have both high certainty and substantial magnitude of net benefit, it is assigned a grade of A, while a finding of the same degree of certainty with a moderate benefit is assigned a grade of B, that with a small benefit is assigned a C, and zero/negative benefit, a D. Definitions of grades are as follows:

A. There is high certainty that the net benefit is substantial.
B. There is high certainty that the net benefit is moderate or there is moderate certainty that the net benefit is moderate to substantial.
C. There is at least moderate certainty that the net benefit is small.
D. There is moderate or high certainty that the service has no net benefit or that the harms outweigh the benefits.

In the absence of a grade, an I (Insufficient) statement indicates that current evidence is insufficient to assess the balance of benefits and harms of the service and that evidence is lacking, of poor quality, or conflicting, and the balance of benefits and harms cannot be determined.

EVIDENCE-BASED RECOMMENDATIONS

The USPSTF publishes its recommendations for pediatric prevention and screening in its *Guide to Clinical Preventive Services*. Grade definitions now include recommendations for practice.

A. The USPSTF recommends the service and suggests that physicians offer or provide this service.
B. The USPSTF recommends the service and suggests that physicians offer or provide this service.
C. The USPSTF recommends selectively offering or providing this service to individual patients based on professional judgment and patient preferences and that physicians offer or provide this service for selected patients depending on individual circumstances.
D. The USPSTF recommends against the service and urges physicians to discourage the use of this service.

In the absence of a grade, an I (Insufficient) statement indicates that the USPSTF concludes that the current evidence is insufficient to assess the balance of benefits and harms of the service. If the physician opts to offer the service, patients should understand the uncertainty about the balance of benefits and harms.

Examples of USPSTF recommendations for childhood screening and their grade classification include the following:

- Evidence is insufficient to make a recommendation for blood lead screening in asymptomatic children aged 1 to 5 years who are at increased risk (I). No screening is recommended for same-aged children at average risk (D).

- Screening for hearing loss is recommended in all newborn infants (B).
- Evidence is insufficient to make a recommendation for iron deficiency anemia screening in asymptomatic children aged 6 to 12 months (I).
- Evidence is insufficient to make a recommendation for screening for lipid disorders in asymptomatic infants, children, and adolescents (I).
- Screening is recommended for major depressive disorder in children and adolescents when systems for diagnosis, treatment, and follow-up are in place (B).
- Screening children aged 6 years and older for obesity is recommended (B).
- Screening children aged 3 to 5 years for vision impairment is recommended (B).
- Screening for congenital hypothyroidism, phenylketonuria, and sickle cell disease is recommended in all newborn infants (A).

In addition to the USPSTF, other organizations provide evidence-based recommendations for screening procedures. Examples include the AAP (www.aappublications.org/policy), the Canadian Task Force on Preventive Care (canadiantaskforce.ca), and the American College of Medical Genetics (www.acmg.net). The AAP, in collaboration with the Maternal and Child Health Bureau, has incorporated its recommendations for screening within preventive care in *Bright Futures: Guidelines for Health Supervision of Infants, Children, and Adolescents,* 3rd ed.

SELECTIVE SCREENING OPTIONS

Selective, as opposed to universal, screening may be preferred for certain conditions to enable targeting of select subpopulations deemed to be at greater risk. For example, reported differences in blood lead levels between children living in urban and suburban areas have been cited to support a strategy of geographic targeting. In recognition of the greater risk of exposure among children of families of lower socioeconomic status, Medicaid requires blood lead screening of all children at 12 and 24 months of age. Selective screening programs may target a specific racial or ethnic group that has an increased prevalence of a particular disorder. For example, screening programs for Tay-Sachs disease target Ashkenazi Jews. However, selective screening may fail to identify certain affected individuals. For example, selective screening programs targeting a specific racial or ethnic group are unlikley to identify all infants who have sickle cell disease because defining an individual's racial or ethnic background reliably by surname, self-report, or physical characteristics is often not possible. Because prophylactic administration of penicillin and pneumococcal conjugate vaccine have been demonstrated to reduce morbidity and mortality in young children who have sickle cell anemia, universal screening of all newborns is recommended, regardless of race or ethnic background.

HIGH-RISK REGISTER

Before 1994, the Joint Committee on Infant Hearing, composed of representatives from audiology, otolaryngology, pediatrics, and nursing, favored the use of a register instead of screening to identify infants at risk for hearing impairment. The registry listed specific conditions that place a newborn at increased risk for hearing loss (eg, a family history of hearing loss, anomalies of the head and neck, and a birth weight less than 1,500 grams). Listing these high-risk factors in the form of a screening questionnaire and asking parents to complete the form after delivery was followed by selective AABR testing for infants considered at risk. Because risk-factor screening identifies only 50% of infants who have significant hearing loss, the Joint Committee now recommends the universal screening of all infants before discharge from the newborn nursery. The AAP has also endorsed the implementation of universal newborn hearing screening. In general, experts do not recommend such strategies as high-risk registers as alternatives to screening.

PARENT-COMPLETED QUESTIONNAIRES AND PROFESSIONALLY ADMINISTERED TOOLS

Standardized and validated screening tools for developmental delays include both parent-completed questionnaires and professionally administered tests. Parent-report measures involve the child's caregiver completing a screening tool that typically includes parents' concerns, developmental-behavioral milestones, and both protective and risk factors. Professionally administered tests require a trained clinician to observe the child or demonstrate developmental-behavioral skills and milestones. Time constraints, logistics, and training contribute to the preference of many physicians and their practices for parent-completed questionnaires. Select examples of parent-completed questionnaires designed for use in developmental screening include the Ages and Stages Questionnaires, Third Edition (ASQ-3); the Child Development Inventories (CDI); and the Parents' Evaluation of Developmental Status (PEDS). Examples of professionally administered tools include the Bayley Infant Neurodevelopmental Screener (BINS), the BRIGANCE II Screens, and the Denver II. Screening requirements of many states and Medicaid, as well as the availability of reimbursement for developmental screening activities, have increased the use of developmental screening tools in practice settings.

AN INTEGRATED APPROACH TO EARLY DETECTION AND INTERVENTION

Screening is most effective when viewed as a component in an integrated approach to early detection and intervention. For example, the Advisory Committee on Childhood Lead Poisoning Prevention of the CDC recommends that all children and their families receive a combination of screening questions, outreach, and education to minimize exposures prior to blood lead testing. The AAP recommends that early detection of developmental problems is best performed through the process of developmental surveillance and screening. Surveillance is a flexible, longitudinal, continuous, and cumulative process whereby knowledgeable professionals repeatedly observe children

during the provision of child health supervision over time. The components of surveillance include eliciting and attending to parents' concerns; documenting and maintaining a developmental history; making accurate observations of children; identifying risk and protective factors; maintaining an accurate record and documenting the process and findings; and, especially when concerns arise, soliciting input from others who know the child (eg, child care provider, home visitor, preschool teacher). In addition to these longitudinal activities, screening using valid parent-completed questionnaires or professionally administered tools is recommended at 9, 18, and 24 to 30 months of age. The AAP also recommends the use of an autism-specific screening tool (eg, Modified Checklist for Autism in Toddlers [M-CHAT]) for condition-specific screening at 18 and 24 months of age. Surveillance and screening enables the physician to interpret the results of screening in the context of all that is known about the child and family.

Screening processes should ensure the proper interpretation of screening results, as well as assessment and intervention for children identified as at increased risk through the screening process. Screening should be viewed as one component in an integrated approach to connecting children with services. Federal and state agencies are increasingly encouraging the role of screening in a systems approach that includes screening, early identification, referral, intake, evaluation and eligibility, and services. Despite increases in the use of screening tools in the practice setting, children with positive screens are not consistently referred for assessment, and those found to be in need of intervention may not be linked to services. Comprehensive systems must support each step in this critical process to ensure that screening is beneficial for children and their families.

APP POLICY

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Chapter 26

AUDITORY SCREENING

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JUSTIFICATION FOR SCREENING

Hearing loss is a common congenital condition in newborns. It is 20 times more prevalent than phenylketonuria and occurs twice as often as hypothyroidism, galactosemia, phenylketonuria, and sickle cell disease combined. Routine screening for hearing loss is a justifiable procedure based on the prevalence of the disorder in the general pediatric population and at-risk groups along with the availability of effective interventions. Between 1 and 6 per 1,000 babies without risk factors and approximately 13.3 per 1,000 babies with high-risk factors are born with hearing loss greater than 40 dB. However, these estimates fail to account for babies who have mild (<40 dB) sensorineural hearing losses. Add to this number children with progressive hearing losses and acquired childhood hearing losses, and the importance of infant and childhood hearing screening is undeniable.

Approximately 14.9% of all children in the United States have a hearing loss with thresholds of at least 16 dB HL. Any hearing loss, including a minimal degree of loss (15–25 dB), may cause speech and language delay and difficulty in social and educational environments (see Chapter 195, Speech and Language Concerns). The consequences are profound: approximately 37% of children with a mild sensorineural hearing loss will fail at least 1 grade in school. Late-identified children with bilateral, permanent hearing loss leave the educational system at the age of 18 years having achieved, on average, a sixth-grade reading level and a language-age equivalent of 12 years. These developmental delays have been found to result in reduced educational and employment levels in adulthood.

To maximize communicative competence and literacy in children who are hard of hearing or deaf, the Joint Committee on Infant Hearing (JCIH) published a position statement (endorsed by the National Institutes of Health [NIH] and the American Academy of Pediatrics [AAP]) recommending an agenda of early hearing detection and intervention. The Committee endorsed the goal of testing children by 1 month of age, identifying those with hearing loss by 3 months

of age, and initiating intervention for children who are deaf or hard of hearing by 6 months of age, as suggested in the landmark 1998 study by Yoshinaga-Itano and colleagues. Despite the evidence that early identification and intervention are critical to the overall communicative, cognitive, educational, and emotional development of children with hearing loss, the average age of identifying early-onset hearing loss in the United States was between 12 and 25 months before implementation of Universal Newborn Hearing Screening (UNHS). However, it may be improving. Recent studies have reported the average age of diagnosis of hearing loss to be as young as 3.7 months after implementation of UNHS. Early intervention in the form of audiologic management, otologic treatment, amplification, parental counseling, and special education is important not only because of the seriousness of the medical sequelae of active otopathologic conditions, but also because of the negative consequences that even a mild hearing loss has for language growth, academic success, and behavioral development.

GOALS OF SCREENING

The goal of hearing screening programs in general is to identify children with hearing loss as early as possible to prevent the detrimental effects that late diagnosis has on language and speech development. Approximately 40% to 50% of infants with hearing loss would remain unidentified if high-risk indicators were used as a screening method instead of direct testing of all children. In 1993, the NIH Consensus Development Conference recommended that all babies be screened for hearing loss before being discharged from the hospital. As of 2005, all 50 states and the District of Columbia had Early Hearing Detection and Intervention (EHDI) programs in place. The primary responsibilities of the EHDI staff are to manage a system of services that ensures children born with permanent hearing loss are identified by 3 months of age and provided with intervention services before 6 months of age. However, at the time of this publication, only 43 states have legislation in place requiring mandatory UNHS, the goal of which is to detect moderate to severe hearing loss. (State-specific information is available through the National Center for Hearing Assessment and Management [NCHAM], Utah State University [www.infanthearing.org/index.html].)

NEONATAL AND EARLY INFANT PERIOD

Empirical evidence suggests that the best method for the detection of and subsequent intervention for hearing loss in the neonatal and early infant period is the implementation of a UNHS program (Box 26-1 and Figure 26-1). Regardless of prior screening outcomes, all infants who are at risk for delayed-onset or progressive hearing loss should receive audiologic monitoring every 6 months for the first 3 years of life. (Box 26-2 summarizes the risk factors for hearing loss.) Additionally, all infants with or without risk factors should receive ongoing surveillance of communicative development beginning at 2 months of age during well-child visits.

Based on data suggesting the long-term developmental consequences of hearing loss in infants, the

BOX 26-1 Principles That Provide the Foundation for Effective Early Hearing Detection and Intervention (EHDI) Systems

1. All infants should have access to hearing screening using a physiologic measure no later than 1 month of age.
2. All infants who do not pass the initial hearing screening and the subsequent screening should have appropriate audiologic and medical evaluations to confirm the presence of hearing loss no later than 3 months of age.
3. All infants with confirmed permanent hearing loss should receive early intervention services as soon as possible after diagnosis, but no later than 6 months of age. A simplified, single point of entry into an intervention system appropriate for children with hearing loss is optimal.
4. The EHDI system should be family centered with infant and family rights and privacy guaranteed through informed choice, shared decision making, and parental consent in accordance with state and federal guidelines. Families should have access to information about all intervention and treatment options and counseling regarding hearing loss.
5. The child and family should have immediate access to high-quality technology, including hearing aids, cochlear implants, and other assistive devices when appropriate.
6. All infants and children should be monitored for hearing loss in the medical home. Continued assessment of communication development should be provided by appropriate professionals to all children with or without risk indicators for hearing loss.
7. Appropriate interdisciplinary intervention programs for infants with hearing loss and their families should be provided by professionals knowledgeable about childhood hearing loss. Intervention programs should recognize and build on strengths, informed choices, traditions, and cultural beliefs of the families.
8. Information systems should be designed and implemented to interface with electronic health records and should be used to measure outcomes and report the effectiveness of EHDI services at the patient, practice, community, state, and federal levels.

From Joint Committee on Infant Hearing, American Academy of Audiology, American Academy of Pediatrics, American Speech-Language-Hearing Association, Directors of Speech and Hearing Programs in State and Welfare Agencies. Year 2007 position statement: principles and guidelines for early hearing detection and intervention programs. *Pediatrics*. 2007;120:898–921.

JCIH defines the targeted hearing loss for UNHS programs as permanent bilateral or unilateral, sensory, or conductive hearing loss averaging 40 dB in the frequency region that is important for speech recognition (approximately 500–4,000 Hz). This guideline generally eliminates from identification children with transient conductive hearing losses and mild sensory or conductive hearing loss, as well as those with hearing loss related to auditory neuropathy or neural conduction disorders, which makes audiologic monitoring and routine screening later in life even more important. This issue will be discussed in more detail in later sections of this chapter. Objective physiologic measures must be used to identify newborns and young infants with hearing loss. Although different programs use different screening criteria and a conclusive recommendation has yet to be reached, the literature suggests that otoacoustic emissions (OAEs) and auditory brainstem response (ABR) measures used together provide much more accurate information than either test alone and that both are necessary for a comprehensive screening program. Northern and Hayes report that using a 2-stage OAE-ABR screening protocol will result in only 1.7 infants with normal hearing being referred for a complete diagnostic evaluation for every baby who has hearing loss (based on a prevalence rate of 2 to 3 hearing-impaired infants per 1,000 births). In other words, the 2 screening technologies are complementary when used in a 2-stage screening protocol. Regardless of the protocol used, studies indicate that the best time frame for UNHS programs is approximately 3 to 4 days after birth. Korres and colleagues reported that the highest referral rates occur within the first 24 hours of life. Hall and colleagues (2010) reported the average length of stay after delivery is approximately 2.6 days; thus, testing is often completed prior to an ideal time frame, which may increase referral rates. The 2007 JCIH position statement recommends different protocols for the neonatal intensive care unit and well-baby nurseries. Screening of babies in the neonatal intensive care unit admitted for more than 5 days should always include ABR testing because of their increased risk for

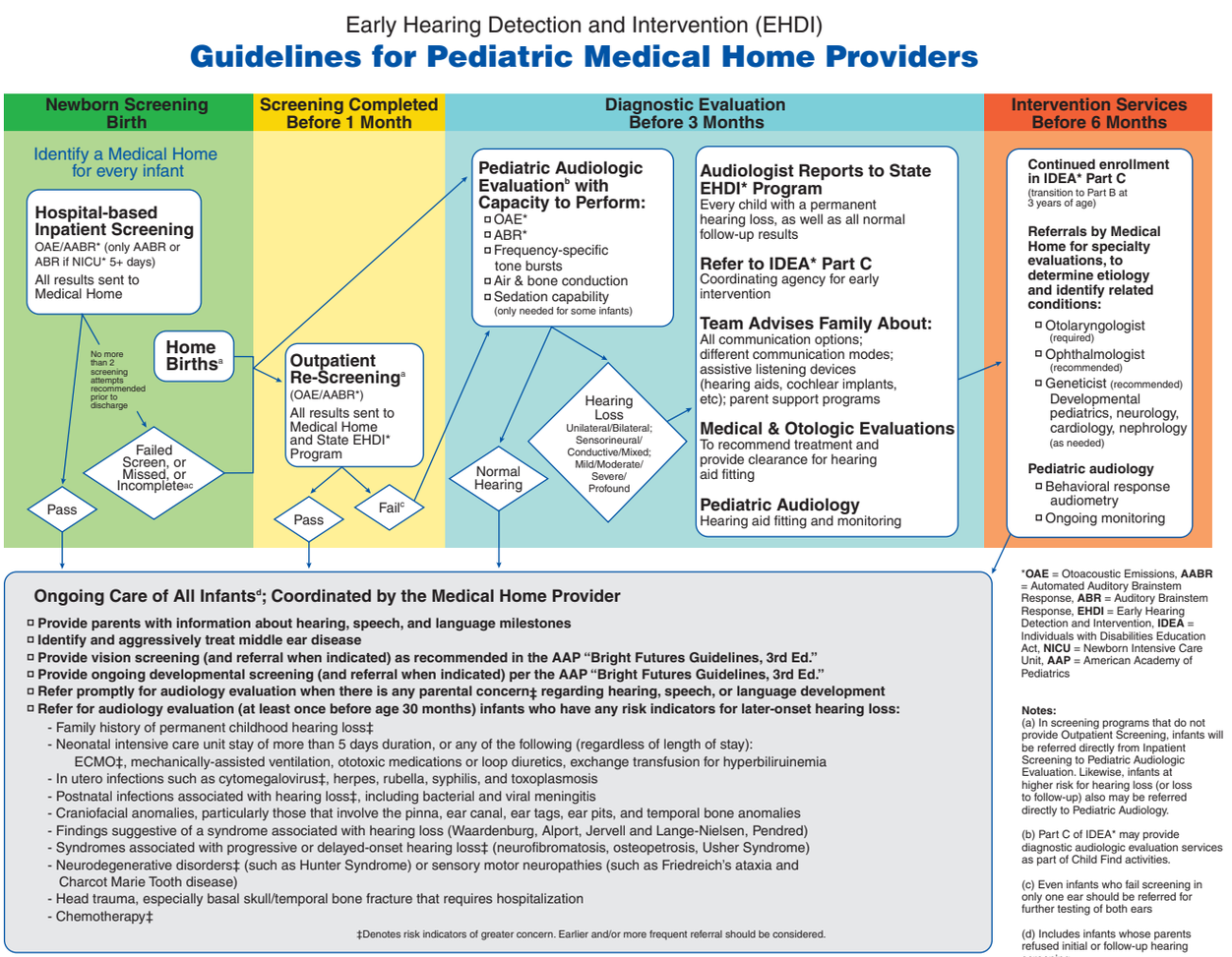
Early Hearing Detection and Intervention (EHDI)
Guidelines for Pediatric Medical Home Providers
Newborn Screening Birth
Screening Completed Before 1 Month
Diagnostic Evaluation Before 3 Months
Intervention Services Before 6 Months
Identify a Medical Home for every infant
Hospital-based Inpatient Screening
OAE/AABR* (only AABR or ABR if NICU* 5+ days)
All results sent to Medical Home
No more than 2 screening attempts recommended prior to discharge
Home Births[a]
Failed Screen, or Missed, or Incomplete[ac]
Pass
Outpatient Re-Screening[a]
(OAE/AABR*)
All results sent to Medical Home and State EHDI* Program
Pass
Fail[c]
Pediatric Audiologic Evaluation[b] with Capacity to Perform:
OAE*
ABR*
Frequency-specific tone bursts
Air & bone conduction
Sedation capability
(only needed for some infants)
Normal Hearing
Hearing Loss
Unilateral/Bilateral; Sensorineural/ Conductive/Mixed; Mild/Moderate/ Severe/ Profound
Audiologist Reports to State EHDI* Program
Every child with a permanent hearing loss, as well as all normal follow-up results
Refer to IDEA* Part C
Coordinating agency for early intervention
Team Advises Family About:
All communication options; different communication modes; assistive listening devices (hearing aids, cochlear implants, etc); parent support programs
Medical & Otologic Evaluations
To recommend treatment and provide clearance for hearing aid fitting
Pediatric Audiology
Hearing aid fitting and monitoring
Continued enrollment in IDEA* Part C
(transition to Part B at 3 years of age)
Referrals by Medical Home for specialty evaluations, to determine etiology and identify related conditions:
Otolaryngologist (required)
Ophthalmologist (recommended)
Geneticist (recommended)
Developmental pediatrics, neurology, cardiology, nephrology
(as needed)
Pediatric audiology
Behavioral response audiometry
Ongoing monitoring
Ongoing Care of All Infants[d]; Coordinated by the Medical Home Provider
Provide parents with information about hearing, speech, and language milestones
Identify and aggressively treat middle ear disease
Provide vision screening (and referral when indicated) as recommended in the AAP "Bright Futures Guidelines, 3rd Ed."
Provide ongoing developmental screening (and referral when indicated) per the AAP "Bright Futures Guidelines, 3rd Ed."
Refer promptly for audiology evaluation when there is any parental concern‡ regarding hearing, speech, or language development
Refer for audiology evaluation (at least once before age 30 months) infants who have any risk indicators for later-onset hearing loss:
- Family history of permanent childhood hearing loss‡
- Neonatal intensive care unit stay of more than 5 days duration, or any of the following (regardless of length of stay):
ECMO‡, mechanically-assisted ventilation, ototoxic medications or loop diuretics, exchange transfusion for hyperbiliruinemia
- In utero infections such as cytomegalovirus‡, herpes, rubella, syphilis, and toxoplasmosis
- Postnatal infections associated with hearing loss‡, including bacterial and viral meningitis
- Craniofacial anomalies, particularly those that involve the pinna, ear canal, ear tags, ear pits, and temporal bone anomalies
- Findings suggestive of a syndrome associated with hearing loss (Waardenburg, Alport, Jervell and Lange-Nielsen, Pendred)
- Syndromes associated with progressive or delayed-onset hearing loss‡ (neurofibromatosis, osteopetrosis, Usher Syndrome)
- Neurodegenerative disorders‡ (such as Hunter Syndrome) or sensory motor neuropathies (such as Friedreich's ataxia and Charcot Marie Tooth disease)
- Head trauma, especially basal skull/temporal bone fracture that requires hospitalization
- Chemotherapy‡
‡Denotes risk indicators of greater concern. Earlier and/or more frequent referral should be considered.
*OAE = Otoacoustic Emissions, AABR = Automated Auditory Brainstem Response, ABR = Auditory Brainstem Response, EHDI = Early Hearing Detection and Intervention, IDEA = Individuals with Disabilities Education Act, NICU = Newborn Intensive Care Unit, AAP = American Academy of Pediatrics
Notes:
(a) In screening programs that do not provide Outpatient Screening, infants will be referred directly from Inpatient Screening to Pediatric Audiologic Evaluation. Likewise, infants at higher risk for hearing loss (or loss to follow-up) also may be referred directly to Pediatric Audiology.
(b) Part C of IDEA* may provide diagnostic audiologic evaluation services as part of Child Find activities.
(c) Even infants who fail screening in only one ear should be referred for further testing of both ears
(d) Includes infants whose parents refused initial or follow-up hearing screening.
February 2010 - American Academy of Pediatrics Task Force for Improving Newborn Hearing Screening, Diagnosis and Intervention (www.medicalhomeinfo.org)

Figure 26-1 Early Hearing Detection and Intervention (EHDI) Guidelines for Pediatric Medical Home Providers.

BOX 26-2 Risk Indicators Associated With Permanent Congenital, Delayed-Onset, or Progressive Hearing Loss in Childhood[a]

1. Caregiver concern[b] regarding hearing, speech, language, or developmental delay
2. Family history[b] of permanent childhood hearing loss
3. Neonatal intensive care of more than 5 days or any of the following regardless of length of stay: ECMO,[b] assisted ventilation, exposure to ototoxic medications (gentamycin and tobramycin) or loop diuretics (furosemide, lasix), and hyperbilirubinemia requiring exchange transfusion
4. In utero infections, such as CMV,[b] herpes, rubella, syphilis, and toxoplasmosis
5. Craniofacial anomalies, including those involving the pinna, ear canal, ear tags, ear pits, and temporal bone anomalies
6. Physical findings, such as white forelock, associated with a syndrome known to include a sensorineural or permanent conductive hearing loss
7. Syndromes associated with hearing loss or progressive or late-onset hearing loss,[b] such as neurofibromatosis, osteopetrosis, and Usher syndrome; other commonly identified syndromes such as Waardenburg, Alport, Pendred, and Jervell and Lange-Nielson
8. Neurodegenerative disorders,[b] such as Hunter syndrome, or sensorimotor neuropathies, such as Friedreich ataxia and Charcot-Marie-Tooth syndrome
9. Culture-positive postnatal infections associated with sensorineural hearing loss,[b] including confirmed bacterial and viral (especially herpesvirus and varicella) meningitis
10. Head trauma, especially basal skull or temporal bone fracture[b] requiring hospitalization
11. Chemotherapy[b]

CMV, cytomegalovirus; *ECMO*, extracorporeal membrane oxygenation.
[a]Any infant with a risk indicator for hearing loss should be referred for an audiologic assessment at least once by 24 to 30 months of age. Children with risk indicators highly associated with delayed-onset hearing loss, such as having received ECMO or having CMV infection, should have more frequent audiologic assessments.
[b]Risk indicators that are of greater concern for delayed-onset hearing loss.
From Committee on Infant Hearing, American Academy of Audiology, American Academy of Pediatrics, American Speech-Language-Hearing Association, Directors of Speech and Hearing Programs in State and Welfare Agencies. Year 2007 position statement: principles and guidelines for early hearing detection and intervention programs. *Pediatrics*. 2007;120:898–921.

neural hearing loss, including auditory neuropathy. Additionally, any baby readmitted to the hospital within the first month of life who also has risk factors for hearing loss should have a repeat hearing screening before discharge.

Both OAEs and ABRs are noninvasive recordings of the physiologic activity that underlies normal auditory function. Both tests are easily recorded in neonates, although environmental noise and the presence of birth fluids in the ear canal may influence test results. OAEs and ABR testing examine different levels of audition. OAEs provide information regarding the integrity of the outer hair cells. They are rapidly recorded and provide information regarding the presence or absence of hearing loss, but cannot distinguish the degree or type of hearing loss. OAEs are also generally absent in the presence of sensory hearing loss greater than or equal to a 40-dB hearing level. However, OAEs are also sensitive to ear canal obstruction and middle ear effusion and may, therefore, cause a failed test result in the presence of normal cochlear function. Because OAEs examine the integrity of the cochlea, neural dysfunction such as auditory neuropathy or neural conduction disorders without overlaying sensory loss will not be detected. In comparison, ABR testing reflects the activity of the cochlea, the auditory nerve, and the central auditory pathway up to the level of the brainstem. For this reason, the inclusion of ABR as a screening tool is particularly important for neonatal intensive care unit graduates. The test may also be affected by the presence of environmental noise or fluid in the external auditory canal. ABR reflects conductive hearing loss, sensory hearing loss, and neural conduction disorders such as auditory dyssynchrony and neuropathy.

Despite the sensitivity of a 2-step screening protocol, some infants with hearing loss will still be missed. According to the JCIH, some examples of hearing loss types and configurations that are typically missed by current standards include isolated low-frequency (<1,000 Hz) hearing loss or steeply sloping high-frequency (>2,000 Hz) hearing loss. ABR testing can also suggest normal hearing in the presence of mid-frequency (500–2,000 Hz) hearing loss. Acquired or progressive hearing loss will also be unidentified in the neonatal population. Other factors that may result in a false-negative outcome include the performance and recording characteristics of the test technology, the pass-refer criteria, and excessive retesting using the same technology. Even if a child passes the newborn hearing screen, any time there is parental concern of speech language delay, comprehensive diagnostic evaluation by a licensed audiologist should be completed. In 2000, the JCIH and the AAP revised their goals for UNHS protocols to achieve a screening population capture rate of 95%, follow-up rate of 95%, referral rate of less than 4%, and false-positive rate less than 3%, all confirmed by 3 months of age and with intervention occurring by 6 months of age. If 95% of babies born are screened for hearing loss, as the JCIH recommends, then technology and protocols to screen for hearing loss at birth can detect approximately 90% of those with hearing loss. The primary

factor contributing to the effectiveness of hearing screening is appropriate follow-up. This critical issue is further explored in later sections of this chapter.

TODDLER AND PRESCHOOL PERIOD (2–5 YEARS)

In the toddler and preschool periods, the screening protocol is modified to include the identification of otopathologic abnormalities (especially otitis media with effusion), mild conductive hearing loss, and previously undiagnosed, acquired, or progressive sensorineural hearing loss. Routine periodic screening of school-aged children is recommended to ensure hearing that is optimal for educational participation. Although the method of screening children in these age groups has not changed significantly, awareness of and sensitivity to the effects of hearing loss on skill development and educational achievement is far greater.

The primary goal of screening in the 2- to 5-year-old period is the detection of medically remediable otopathologic abnormalities, progressive hearing loss, or late-onset acquired hearing loss. Furthermore, parents and pediatricians should recognize that children with mild hearing loss are typically missed by UNHS programs. Screening procedures for young children are performed with the assumption that the more severe sensorineural hearing losses will have been identified by age 2 years. However, 20% to 30% of hearing loss in children up to age 18 years is acquired or progressive, and 75% of children will have at least one episode of otitis media by their third birthday. Even though this age group is particularly difficult to screen, obtaining accurate results is nonetheless important in this population. The principal cause of hearing loss in this age range is otitis media, a pathologic abnormality capable of producing subtle but significant auditory learning disorders and permanent middle-ear damage. Additionally, many conditions place children at risk for late-onset or progressive hearing loss (see Box 26-2); thus, these conditions also must be considered when screening this population.

Children in this age group are usually screened for hearing loss at well-baby clinics, pediatricians' offices, Head Start programs, and preschool programs. Although the screening procedures may differ from site to site depending on the availability of equipment and trained personnel and on the level of background noise in the screening environment, the ideal protocol would include the following elements:

1. Physical examination.
2. A detailed family history.
3. Acoustic immittance testing (tympanometry).
4. Otoscopic inspection of the ear canal.
5. Pure tone sweep at 1,000, 2,000, and 4,000 Hz at 20 dB HL for children aged 3 years and older (or OAEs, only for children who cannot condition to behavioral testing) completed by trained professionals.
6. An elicitation of parental or caregiver concern about the child's hearing and speech and language development. The importance of this element should not be underestimated. According to the NIH, 70% of children with acquired hearing loss are initially identified by parents. Parents are typically as much as 12 months ahead of physicians in identifying their child's hearing loss. Thus, the NIH stresses that parental concern regarding hearing is sufficient reason to initiate prompt, formal, comprehensive hearing evaluation.
7. Failure to attain appropriate language milestones should result in prompt referral for further hearing evaluation by a licensed pediatric audiologist.

Although behavioral, ear-specific responses are the gold standard of hearing screening for this age group, for children who are unable to participate in behavioral procedures, screening with OAEs is acceptable, although even a mild conductive component may obscure results. Screening stimuli that lack frequency-specificity or behavioral observation techniques based on noncalibrated signals, such as rattles, music boxes, noisemakers, whisper tests, and finger-rub tests, among others, are neither recommended nor acceptable. Behavioral testing for children up to 36 months old can be conducted using visual reinforcement audiometry, whereas children older than 36 months should be able to participate in conditioned play audiometry. Both tests should be performed at a level of 20 dB in a sound booth. Any child who does not respond at this level at any one frequency should be referred for a comprehensive evaluation by a licensed audiologist. A more in-depth discussion of appropriate screening procedures for this age group can be found in the American Academy of Audiology's *Childhood Hearing Screening Guidelines*. Parents, particularly those with a child who is at risk for progressive or acquired hearing loss, should also be counseled regarding auditory and communicative milestones for their child (Box 26-3) so that they may monitor their child's development. All children should receive systematic developmental screening with an objective tool. Any children screening positive for concerns in the language domain should complete an audiologic evaluation.

SCHOOL-AGE PERIOD (5–18 YEARS)

The primary goal of hearing screenings in this age group is identical to that of the toddler-preschool period, with the addition of the maintenance of educationally optimal hearing. Typically, these children are screened in the school setting by trained professionals and are referred to the physician only if they fail the screening. School-aged children should be screened on initial entry into school, annually in kindergarten through third grade, in seventh and eleventh grades, and as needed, requested, or mandated by regulation. In this age group, the most likely cause of hearing abnormality is an otopathologic abnormality; however, some children are still at risk for acquired or progressive hearing loss. At-risk children should be routinely monitored for hearing loss (see Box 26-2). Additionally, during this period, central auditory processing disorders typically become apparent. Children as young as 7 years may be evaluated for central auditory processing disorder by an audiologist. Parent and teacher reports are particularly important during this period and should be regarded seriously. Pediatricians should be aware of local resources for the evaluation and management of central auditory processing disorder.

BOX 26-3 Checklist of Selected Speech-Language-Auditory Milestones Achieved by Infants and Children Who Have Intact Cognition and Hearing

BIRTH TO 3 MONTHS
- Startles to loud noise
- Awakens to sounds
- Blinks or widens eyes in response to new sounds

3 TO 4 MONTHS
- Quiets to mother's voice
- Stops playing; listens to new sounds
- Looks for source of new sounds not in sight

6 TO 9 MONTHS
- Enjoys musical toys
- Coos and gurgles with inflection
- Says, "mama"

12 TO 15 MONTHS
- Responds to the baby's own name and "no"
- Follows simple requests
- Uses expressive vocabulary of 3 to 5 words
- Imitates some sounds

18 TO 24 MONTHS
- Knows body parts
- Uses expressive vocabulary (2-word phrases, minimum of 20 to 50 words)
- Fifty percent of speech intelligible to strangers

BY 36 MONTHS
- Uses expressive vocabulary of 4- to 5-word sentences (approximately 500 words)
- Uses speech that is 80% intelligible to strangers
- Understands some verbs

Failure to achieve these milestones by expected age ranges might relate to hearing loss that necessitates audiologic testing.

Derived from Northern J, Downs M. *Hearing in Children.* 4th ed. Baltimore, MD: Williams & Wilkins; 1991.

The ideal protocol would include the following elements:
1. Otoscopic inspection of the ear canal
2. Acoustic immittance testing (tympanometry)
3. Behavioral testing under calibrated headphones or with insert phones including pure tone sweep at 1,000, 2,000 and 4,000 Hz at 20 dB HL
4. Elicitation of parental or caregiver concern about the child's hearing, speech and language development, and educational performance

Behavioral testing should be performed in the traditional method of hand raising in response to frequency-specific tones (1,000, 2,000, and 4,000 Hz) presented under headphones at 20 dB. Failure to respond at even 1 frequency in 1 ear should result in referral for complete audiometric evaluation by a licensed audiologist. Should failure of acoustic immittance testing occur at both initial testing and retesting 6 weeks later, then referral will be made to the primary care physician for evaluation of middle-ear disorder. A more in-depth discussion of appropriate screening procedures for this age group can be found in the American Academy of Audiology *Childhood Hearing Screening Guidelines*

FOLLOW-UP CARE AND BENEFITS OF TREATMENT

The most critical aspect of an effective screening program is the subsequent follow-up care and treatment of children identified with hearing loss; those who fail their newborn hearing screening; or those labeled as at risk for progressive, late-onset, or acquired hearing loss. If no meaningful intervention and management occurs after hearing screening, or if children with a proclivity to acquired hearing loss are not screened frequently and appropriately, then the program has failed in its primary purpose: initiating a process of timely habilitation. Timely, consistent follow-up is among the greatest challenges to hearing screening programs. In 2009, approximately 45% of children who were referred for a follow-up examination failed to return for it. A combination of administrative error and lack of parental education seem to be to blame. Inadequate data systems, inconsistent reporting requirements, and lack of communication among medical professionals have all been cited as reasons for the poor follow-up rate. In a 2004 study of medical care after school hearing screening, one of the most common barriers to follow-up was that 33% of parents surveyed did not suspect a hearing problem or doubted the screening test accuracy, or both. The importance of parental education cannot be overemphasized. A study conducted by Wittman-Price and Pope in 2002 found that although 97% of parents rated UNHS programs as "very important" on a survey and left the hospital with a scheduled follow-up appointment, only 77% returned their infant for follow-up testing. However, in an intervention group that received a 20-minute educational session on UNHS programs at a prenatal class and received educational literature, 100% of parents of referred infants returned for follow-up testing. Consistent, coordinated medical reporting and management combined with parental education are critical to the success of UNHS and early hearing detection and intervention programs. The AAP developed a checklist and flow chart to assist in the tracking of patients by their medical team (Figure 26-2; see also Figure 26-1). Simple systems such as these are an asset to primary care physicians and other members of the team.

The initial follow-up evaluation for an infant or child who fails a hearing screen or who is at risk for acquired or progressive hearing loss must include a comprehensive audiologic evaluation by a licensed audiologist, the

Early Hearing Detection and Intervention (EHDI)

Patient Checklist for Pediatric Medical Home Providers

Patient Name: _____

Date of Birth: ____/___/____

Birth

Hospital-based Inpatient Screening Results (OAE/AABR) DATE: ____/____/____
(also Home Births)

Left ear:	▫ Missed	▫ Incomplete	▫ Failed Screen[a, c]	▫ Pass
Right ear:	▫ Missed	▫ Incomplete	▫ Failed Screen[a, c]	▫ Pass

Before 1 month

Outpatient Screening Results (OAE/AABR) ____/____/____

Left ear:	▫ Incomplete	▫ Failed Re-Screen[a, c]	▫ Pass
Right ear:	▫ Incomplete	▫ Failed Re-Screen[a, c]	▫ Pass

Before 3 months

▫ **Pediatric Audiology Evaluation**[b] ____/____/____

▫ Hearing Loss ▫ Normal Hearing

- ▫ **Document child and family auditory history** ____/____/____
- ▫ **Report to State EHDI Program** results of diagnostic evaluation ____/____/____
- ▫ **Refer to Early Intervention** (IDEA, Part C) ____/____/____
- ▫ **Advise family** about communication options and assistive listening devices (hearing aids, cochlear implants, etc.) ____/____/____
- ▫ **Medical & Otologic Evaluations** to recommend treatment and provide clearance for hearing aid fitting ____/____/____
- ▫ **Pediatric Audiology** for hearing aid fitting and monitoring ____/____/____

Before 6 months

▫ **Enrollment in Early Intervention (IDEA, Part C)** ____/____/____
(transition to Part B at 3 years of age)

▫ **Medical Evaluations** to determine etiology and identify related conditions
- ▫ Otolaryngology (required) ____/____/____
- ▫ Ophthalmologist (recommended) ____/____/____
- ▫ Geneticist (recommended) ____/____/____
- ▫ Developmental pediatrics, neurology, cardiology, and nephrology (as needed) ____/____/____

▫ **Ongoing Pediatric Audiology Services** ____/____/____

Ongoing Care of All Infants[d]

- ▫ Provide parents with information about hearing, speech, and language milestones
- ▫ Identify and aggressively treat middle ear disease
- ▫ Vision screening and referral as needed
- ▫ Ongoing developmental surveillance/referral
- ▫ Risk indicators for delayed-onset hearing loss: _____

(If risk factors are present, refer for audiology evaluation at least once prior to age 30 months)

Service Provider Contact Information

Pediatric Audiologist:

Early Intervention Service Coordinator:

Other:

Other:

Other:

(a) In screening programs that do not provide Outpatient Screening, infants will be referred directly from Inpatient Screening to Pediatric Audiologic Evaluation. Likewise, infants at higher risk for hearing loss (or loss to follow-up) also may be referred directly to Pediatric Audiology.

(b) Part C of IDEA* may provide diagnostic audiologic evaluation services as part of Child Find activities.

(c) Even infants who fail screening in only one ear should be referred for further testing of both ears

(d) Includes infants whose parents refused initial or follow-up hearing screening.

OAE = Otoacoustic Emissions
AABR = Automated Auditory Brainstem Response
ABR = Auditory Brainstem Response
IDEA = Individuals with Disabilities Education Act
EHDI = Early Hearing Detection & Intervention

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Pediatric Nurse Practitioners

February 2010 - American Academy of Pediatrics Task Force for Improving Newborn Hearing Screening, Diagnosis and Intervention (www.medicalhomeinfo.org)

Figure 26-2 Early Hearing Detection and Intervention (EHDI) Patient Checklist for Pediatric Medical Home Providers.

purposes of which are to assess the integrity of the auditory system, to estimate hearing sensitivity, and to identify all intervention options. At least 1 ABR test is also recommended as part of the complete diagnostic assessment of children younger than 3 years old before a permanent hearing loss can be confirmed. Once a hearing loss or the presence of middle-ear dysfunction has been confirmed by the audiologist, the child should be referred for otologic and medical consultation to determine the cause of the hearing loss, to identify related physical conditions, and to provide recommendations for medical treatment, if appropriate, as well as referrals for other services. Approximately 40% of children with hearing loss have other disabilities.

Evaluations after a failed screening should typically include the following elements for all children to help identify coexisting conditions that may affect learning and development:

1. Complete patient and family history to identify risk factors for hearing loss
2. Physical examination, and possibly laboratory and radiologic tests, to identify malformations or abnormalities of anatomic structures
3. Monitoring of developmental milestones
4. Referral for genetic evaluation and counseling by a medical geneticist
5. Referral to an ophthalmologist to test for visual acuity
6. Speech and language evaluation

In coordination with these comprehensive evaluations, audiologic intervention is usually recommended. Many treatment options are available, depending on the type and degree of the child's hearing loss. Kemper and colleagues noted that specific treatment was recommended for 51% of children who had follow-up appointments after a failed school screening. This number is even higher for those identified after UNHS evaluation. For children with conductive hearing loss, medical and surgical options are often available. In the case of a child with atresia or a similar anatomic condition that precludes medical or surgical treatment, the fitting of a bone-conduction sound processor on a softband or on a surgically implanted abutment (for children older than 5 years) is typically the treatment of choice. Amplification or the use of assistive listening devices is typically recommended for children with sensorineural hearing loss. Children as young as 4 weeks old may be fit with hearing aids

BOX 26-4 Generalized Candidacy Criteria for Cochlear Implantation in Children

12 TO 24 MONTHS

- Profound sensorineural hearing loss in both ears
- Lack of progress in development of auditory skills with appropriate binaural hearing aids
- High motivation and realistic expectations from the family
- Other medical conditions, if present, do not interfere with cochlear implant procedure

25 MONTHS TO 17 YEARS, 11 MONTHS

- Severe-to-profound sensorineural hearing loss in both ears
- Receives limited benefit from hearing aids (speech scores of 30% or less in best-aided condition)
- Lack of progress in development of auditory skills
- High motivation and realistic expectations from family
- No medical contraindications

Derived from Sampaio AL, Araújo MF, Oliveira CA. New criteria of indication and selection of patients to cochlear implant. *Int J Otolaryngol.* 2011; 2011:573968; and Russell JL, Pine HS, Young DL. Pediatric cochlear implantation: expanding applications and outcomes. *Pediatr Clin North Am.* 2013;60(4):841–863.

if appropriate physiologic test results have been obtained. Once diagnosed with a permanent hearing loss, children should be fit with hearing aids within 1 month of identification. Cochlear implantation is often considered for a child with severe to profound hearing loss when the child demonstrates limited benefit from hearing aids (Box 26-4 summarizes the candidacy criteria of the US Food and Drug Administration, which has approved cochlear implantation in children as young as 12 months of age). Audiologic management should be supervised by a licensed audiologist. For all of these children, speech and language assessment and therapy are essential to development and to the attainment of the goal of intelligible speech and adequate receptive language abilities by the time the child enters kindergarten.

Financial concerns should not limit a child's access to intervention services for hearing loss, although it can be challenging to identify viable sources of funding. The Individuals with Disabilities Education Act (IDEA) ensures that children who have hearing loss receive appropriate, family-centered, multidisciplinary intervention services at no charge to the family from birth through the school years. In addition, a variety of options are available to cover the cost of amplification for a child with permanent hearing loss, including private insurance, Medicaid, and the early intervention services provided by IDEA. Specifics vary by state; however, assisting patients in familiarizing themselves with the options they have available is worthwhile. (State-specific information is available at www.infanthearing.org.)

ROLE OF THE PRIMARY CARE PHYSICIAN

According to the JCIH, the AAP, and the NIH, all infants, regardless of newborn hearing screening outcome, should receive ongoing monitoring for the development of age-appropriate auditory behaviors and communication skills. Any infant who demonstrates an auditory or communicative delay should undergo comprehensive audiologic evaluation by a licensed audiologist. Additionally, any child who is at risk for hearing loss should undergo a complete audiologic evaluation at least once by 24 to 30 months of age. Being coordinator, caretaker, and advocate for the patient is the responsibility of the primary care physician. Additionally, because 30% to 40% of children with confirmed hearing loss will demonstrate developmental delays or other disabilities, the pediatrician should monitor developmental milestones and initiate referrals related to suspected disabilities. The pediatrician should strive for consistent medical management of all patients with hearing loss. Most importantly, the primary care physician should be a part of a medical team who, in collaboration with parents, the audiologist, and other health professionals, provides accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally appropriate health care.

CONCLUSION

Hearing is crucial for the development of speech and language skills in children, and the presence of hearing loss can have a negative effect on social, emotional, and educational development. For this reason, hearing screening is a critical component of medical care for infants and children. Efficient screening methods combined with appropriate and timely follow-up and intervention are necessary to achieve the goals of testing by 1 month of age, identifying hearing loss by 3 months of age, and intervening by 6 months of age, all of which are important to provide optimal access to sounds during the most critical periods of development. The implementation of UNHS programs has decreased the average age of identification dramatically. However, taking the lead in the management and coordination of their patients' care is the responsibility of pediatricians and primary care physicians. Routinely referring children who fail their hearing screenings to a licensed audiologist for appropriate follow-up and management of their hearing is particularly important. Without adequate tracking and follow-up, coordinated by a team approach, maximal benefit cannot be achieved.

ACKNOWLEDGMENT

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TOOLS FOR PRACTICE

Community Advocacy and Coordination

- *50 State Summary of Newborn Hearing Screening Laws* (Web page), National Conference of State Legislatures (www.ncsl.org/programs/health/hear50.htm)

- *Funding Resources Through Local Agencies/Programs* (Web page), American Speech Language Hearing Association (www.ncsl.org/research/health/newborn-hearing-screening-state-laws.aspx)

Engaging Patient and Family

- *Causes of Hearing Loss in Children* (fact sheet), American Speech-Language Hearing Association (www.asha.org/public/hearing/disorders/causes.htm?print=1)
- *Children and Hearing Aids* (fact sheet), American Speech-Language Hearing Association (www.asha.org/uploadedFiles/AIS-Hearing-Aids-Children.pdf#search=%22children%22)
- *Early Hearing Detection and Intervention - Pediatric Audiology Links to Services* (Web page), University of Maine (www.ehdi-pals.org)
- *It's Important to Have Your Baby's Hearing Screened* (Web site), National Institute on Deafness and Other Communication Disorders (www.nidcd.nih.gov/health/hearing/pages/screened.aspx)
- *Just in Time So Your Baby's Care Is Right on Time: Early Hearing Detection and Intervention* (handout), Centers for Disease Control and Prevention (www.cdc.gov/ncbddd/ehdi/documents/justintime/136poster.pdf)
- *Parent's Guide to Hearing Loss* (Web site), Centers for Disease Control and Prevention (www.cdc.gov/ncbddd/hearingloss/parentsguide)

Medical Decision Support

- *Childhood Hearing: A Sound Foundation in the Medical Home* (online course), American Academy of Pediatrics (pedialink.aap.org)
- *Childhood Hearing Screening Guidelines*, American Academy of Audiology (www.cdc.gov/ncbddd/hearingloss/documents/aaa_childhood-hearing-guidelines_2011.pdf)
- *Early Hearing Detection and Intervention* (Web page), American Academy of Pediatrics (www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/PEHDIC/Pages/Early-Hearing-Detection-and-Intervention.aspx)
- *The "State" of Early Hearing Detection and Intervention in the United States* (Web page), National Center for Hearing Assessment and Management, Utah State University (www.infanthearing.org/states)
- *Universal Newborn Hearing Screening: Current Testing Techniques* (fact sheet), Gorga M, Eiten L, Boys Town National Research Hospital (www.infanthearing.org/physicianeducation/UNHSFactSheet_Boystown.pdf)
- *Universal Newborn Hearing, Screening, Diagnosis, and Intervention: Guidelines for Pediatric Medical Home Providers* (guideline), American Academy of Pediatrics (www.infanthearing.org/stateguidelines/Maine/Medical%20Guidelines.pdf)

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Chapter 27

SCREENING FOR ANEMIA

Ruchika Sharma, MD; Bryce A. Kerlin, MD

Anemia may be defined by laboratory values (low hemoglobin) or by physiologic consequences (inadequate oxygen-carrying capacity); both are equally important. The World Health Organization (WHO) defines anemia as a hemoglobin (Hb) concentration ≥2 standard deviations (SD) below the mean Hb concentration for a normal population of the same gender and age range. Two commonly encountered pediatric conditions that may be associated with anemia and also meet criteria for screening programs (as outlined in Chapter 25, Screening: General Considerations), are sickle cell disease and iron deficiency.

SCREENING PROGRAMS AND METHODS

Screening for anemia in infants and young children begins shortly after birth via the universal newborn screening programs, which are intended to identify cases of sickle cell disease as early as possible to enable early institution of penicillin prophylaxis. Screening continues in the office practice, emphasizing early detection of iron deficiency and appropriate implementation of nutritional counseling and iron supplementation. The latter is generally accomplished by determining the whole-blood Hb concentration, using blood obtained by finger or heel stick. The sample may be analyzed in the primary care office setting using a small portable spectrophotometer or one of the many bench-top particle counters now available. By either method, the procedure is quick and reliable, with minimal quality control and maintenance required. The Hb concentration is then compared with reference values for age- and gender-matched normal children. Hemoglobin levels that are less than the lower reference limit are defined as anemic.

Positive screening tests for anemia must be confirmed and correlated with the clinical presentation. Patients with anemia may present with signs and symptoms such as fatigue, decreased work or school performance, slow cognitive and social development during childhood, headaches, dizziness, pica, glossitis, stomatitis, pallor, or koilonychia (spooning of nails). Additional information that is relevant to the anemic patient is a history of neonatal jaundice, ethnicity, dietary intake, and family history of splenectomy, cholecystectomy, iron therapy, or blood transfusions. Information about the morphologic characteristics of the patient's red blood cells should also be obtained to guide further diagnostic evaluation. Confirmation usually is performed by submitting a venous blood sample anticoagulated with ethylenediaminetetraacetic acid (EDTA) to the hematology laboratory for a complete blood count (CBC) and microscopic examination of a Wright-stained peripheral blood smear. When abnormal hemoglobins are detected on the newborn screen, confirmatory Hb electrophoresis should be performed between 6 and 12 months of age.

For a complete discussion of the differential diagnosis, evaluation, and management of anemic children, see Chapter 128, Anemia and Pallor.

BOX 27-1 Benefits of Screening for Sickle Cell Disease

- Screening can be accomplished using small quantities of blood and minimal risk to patients.
- Incorporation of Hb screening into existing newborn screening infrastructure allows cost efficiencies.
- Newborn Hb screening uses sensitive methods.
- Without screening, sickle cell disease may go undetected until the child presents with a life-threatening complication.
- Measures are available to prevent life-threatening complications in children identified early. These include:
  - Penicillin prophylaxis (125 mg orally twice daily)
  - Education (including parental ability to correctly palpate splenic size)
  - Referral to a pediatric hematology program for appropriate health surveillance under the guidance of hemoglobinopathy experts.
  - Timely immunization.
- Early identification also provides an opportunity for genetic counseling before a subsequent pregnancy.

SCREENING FOR SICKLE CELL DISEASE

Epidemiology and Clinical Importance

Sickle cell disease is a common hereditary blood disorder in the United States, affecting an estimated 100,000 Americans. Identifying sickle cell disease early through newborn screening helps to prevent deaths and complications of the disease, such as fatal infections (eg, pneumococcal sepsis), splenic sequestration, and acute chest syndrome. The early detection of sickle cell disease through newborn screening, coupled with rapid institution of penicillin prophylaxis, has helped prevent death and other complications, including a dramatic decrease in the incidence of fatal pneumococcal sepsis in this population. Although sickle cell disease is the driving force behind these screening programs, other less common conditions that may be identified through this procedure include α-thalassemia and severe forms of β-thalassemia.

Benefits of Screening

With the advancement of newborn screening programs, there is now universal screening for sickle cell disease in the United States. These programs evolved from the basic tenets of newborn screening, inexpensive screening assays for common diseases for which an early intervention (penicillin) has been proved to improve overall outcomes. Therefore, the Hb screening program is focused on the early identification of infants afflicted with sickle cell disease. Box 27-1 summarizes the benefits of screening and early identification in these conditions.

Managing a Positive Screen

All 50 US states and the District of Columbia now require screening for sickle cell disease through their respective newborn screening programs; many states also report variant hemoglobins identified incidentally during the screening process. Many of the variant hemoglobins are benign, particularly when heterozygous; a search engine provided by the Globin Gene Server (see Tools for Practice) is a useful tool for both the pediatrician and the pediatric hematologist when determining their clinical relevance. Although newborn screening improves the sensitivity of detection for α-thalassemia, some forms of β-thalassemia may not be detectable until after Hb switching from fetal forms (at the γ δ β -globin gene locus) has been completed, usually by 6 to 12 months of age. Consultation with a pediatric hematologist who is knowledgeable in hemoglobinopathies and thalassemic conditions may facilitate the interpretation of the potential clinical significance of variant hemoglobins and potential thalassemia cases.

Hemoglobins detected on newborn screening are typically presented in descending order of concentration within the specimen. Hb F ($\alpha_2\gamma_2$) is almost always the most prevalent hemoglobin in an untransfused newborn and thus is usually the first, followed by additional species in order of prevalence when reading from left to right. Table 27-1 presents typical newborn screening results and their appropriate interpretation.

Based on these results, pediatricians should provide education and counseling to the family or refer them to a pediatric hematologist. The parents of children with an FAS pattern (sickle cell trait) should be referred to a genetic counselor from whom they can gain additional education regarding their risk for having a child with sickle cell disease and become informed regarding the effect of carriership for their children's children. These patients typically do not need to see a hematologist, although many pediatric sickle cell programs have a genetic counselor on staff who may provide the above services.

Table 27-1 Newborn Screening Hemoglobin Results and Interpretation

HEMOGLOBINS	INTERPRETATION
FA	Normal (predominantly Hb F [$\alpha_2\gamma_2$], some Hb A [$\alpha_2\beta_2$])
FAS	Sickle cell trait (predominantly Hb F, some Hb A, with less Hb S [$\alpha_2\beta^S{}_2$])
FS	Sickle cell disease (predominantly Hb F, some Hb S)
FSC	Sickle cell disease (predominantly Hb F, some Hb S, with less Hb C [$\alpha_2\beta^C{}_2$])
FSA	Sickle cell disease with β^+-thalassemia (predominantly Hb F, some Hb S, with less Hb A)
+ Barts	α-Thalassemia (Barts Hb [γ_4])

Children with an FS, FSC, or FSA pattern have some form of sickle cell disease and should be prescribed penicillin prophylaxis (125 mg orally twice daily) as early as possible—optimally by 8 weeks of age—and be referred to a pediatric sickle cell program on discovery. Children with an FS pattern will likely have 1 of 2 forms of severe sickle cell disease, either Hb SS (homozygous β^S) or Hb Sβ^0-thalassemia (compound heterozygote for β^S and a β-thalassemia major mutation). Children with an FSC pattern also will have a severe form of sickle cell disease, Hb SC, caused by compound heterozygosity for both β^S and β^C. In contrast, children with an FSA pattern, who still express some normal adult Hb A (usually owing to compound heterozygosity for β^S and a β-thalassemia minor mutation) can be expected to have a milder course of disease.

Counseling should include education on the importance of adherence to the penicillin prophylaxis regimen, emphasizing the dramatic role that this simple intervention has played in reducing early sickle-related mortality, and guidance to seek medical attention immediately for any febrile illness, which may include admission for empirical parenteral antibiotic therapy, while excluding systemic infection. Moreover, the parents should receive instruction on how to appropriately palpate spleen size and be told to do so if their child is ill or appears pale. Whenever the spleen is enlarged beyond baseline, medical attention should be sought immediately for evaluation and treatment of a potential splenic sequestration crisis, which may include an emergent blood transfusion to reverse the process.

Children with Barts Hb should be followed closely and a careful family history taken to determine whether either or both parents have a history of anemia or have been diagnosed with α-thalassemia. There are 4 α-globin genes, 2 paternal and 2 maternal. Often these children have either a single or double gene mutation. Single gene mutations result in a "silent carrier" state in which there are usually no detectable, clinically meaningful changes in their blood count profile, although they may have a slightly lower mean corpuscular volume (MCV). Children with 2 mutated genes have α-thalassemia trait. These patients usually have a mild microcytic-hypochromic anemia (low MCV and mean corpuscular hemoglobin concentration [MCHC]) but rarely require therapy. Iron supplementation should be avoided because of a risk for eventual iron overload with long-term therapy, which will not correct the anemia. Some children, usually of Asian descent, have 3 deleted genes, leading to a severe form of transfusion-dependent anemia called Hb H (β_4) disease. These children will become progressively anemic and should be referred to a hematologist for evaluation and long-term management. Four gene deletions result in hydrops fetalis; thus, these fetuses rarely survive pregnancy.

Additional information on the care and management of children with sickle cell and thalassemia disorders can be found in Chapter 262, Hemoglobinopathies and Sickle Cell Disease.

BOX 27-2 Benefits of Screening for Iron-Deficiency Anemia

- Iron deficiency is the most common nutritional deficiency.
- Iron deficiency has clinically significant consequences.
- Iron deficiency may go undetected without screening.
- Measurement of Hb is the most cost-effective method to screen for iron deficiency.
- Screening is convenient in the context of routine health supervision in the primary care setting.
- More sensitive and specific markers for iron deficiency may be used to confirm the diagnosis.
- Effective treatment for iron deficiency is available.

SCREENING FOR IRON DEFICIENCY

Epidemiology and Clinical Importance

As the most commonly encountered nutritional deficiency in the world, iron deficiency is a significant public health issue. According to the National Health and Nutrition Examination 1999–2000 survey, the estimated prevalence of iron-deficiency anemia in the United States among young toddlers aged 1 to 2 years is 7%, increasing to 9% to 16% among adolescents and adult women of childbearing age, respectively (www.cdc.gov/mmwr/preview/mmwrhtml/mm5140a1.htm).

Benefits of Screening

Screening for anemia is the most reliable and cost-effective method for detecting occult iron deficiency (Box 27-2). Iron deficiency is associated with fatigue, neurocognitive delay, reduced physical capacity, and

exercise intolerance. For these reasons, inadequate iron levels should be detected and treated as early as possible. Thus, iron deficiency is the major impetus behind public health recommendations for office-based anemia screening programs as a part of health maintenance visits.

The overall incidence of iron-deficiency anemia in the United States has been decreasing over the past several decades. This decline has been attributed to use of iron-fortified formulas and iron-fortified infant foods provided by the Special Supplemental Program for Women, Infants, and Children (WIC) beginning in the early 1970s and the decrease in use of whole cow milk for infants. Thus encouragement of these dietary practices should be included in routine health counseling. Iron requirements are highest for infants and adolescents because of the increased growth velocity at these stages of development. Therefore, these children are at greatest risk for occult iron deficiency, and particular attention to appropriate dietary recommendations and indications for iron supplementation is essential. A comprehensive discussion of suitable dietary and supplementation recommendations is maintained by the Centers for Disease Control and Prevention *Morbidity and Mortality Weekly Report Recommendations and Reports* (www.cdc.gov/mmwr/preview/mmwrhtml/00051880.htm).

Bright Futures Recommendations

Among children, iron deficiency is seen most often between 6 months and 3 years of age, owing to rapid growth and inadequate intake of dietary iron. Early detection of iron deficiency is important because occult iron deficiency may be associated with neurocognitive delay and impaired immune function. The American Academy of Pediatrics (AAP) recommends initial measurement of Hb or hematocrit for all full-term infants between 9 and 12 months of age. Preterm and low-birth-weight infants who are fed non–iron-fortified formula should be screened before 6 months of age. Children with underlying risk factors (Box 27-3) should be screened again at 15 to 18 months of age. Starting in adolescence, all nonpregnant women should be screened for anemia every 5 to 10 years throughout their childbearing years during routine health examinations, and those with risk factors for iron deficiency (eg, extensive menstrual or other blood loss, low iron intake, or a previous diagnosis of iron-deficiency anemia) should be screened annually. Adolescent males need to be screened for anemia only in the presence of risk factors.

BOX 27-3 Children at Risk for Iron-Deficiency Anemia

- Preterm and low-birth-weight infants
- Infants fed with cow milk before age 12 months
- Breastfed infants not receiving iron supplementation after age 6 months
- Formula-fed infants who do not receive iron-fortified formulas
- Children aged 1 to 5 years who ingest more than 24 ounces of cow's milk per day
- Children with special health care needs
- Children with low socioeconomic status

Managing a Positive Screening Result

When a low Hb is detected during routine screening in the office practice, a definitive diagnosis should be sought. The first step is to confirm the presence of anemia by requesting a complete blood count (see Screening Programs and Methods). Iron-deficiency anemia will typically have microcytic-hypochromic indices (low MCV and MCHC), with a high red-cell distribution width. An associated thrombocytosis is commonly observed, although thrombocytopenia may also be seen in severe cases. Other types of anemia that should be included in the differential diagnosis of microcytic anemia include thalassemia, sickle-thalassemia diseases, some hemoglobinopathies (eg, C and E), hereditary pyropoikilocytosis, severe lead intoxication, and the anemia of chronic disease. The differential diagnosis, evaluation, and management of normocytic (normal MCV) and macrocytic (elevated MCV) anemias are considered in Chapter 128, Anemia and Pallor.

For mild microcytic anemia (ie, Hb 8 to 10 g/dL), empirical treatment with iron supplementation (3 to 4 mg elemental iron/kg of body weight/day) is appropriate. Iron therapy, in combination with dietary strategies to increase iron and vitamin C intake (to enhance iron absorption), effectively treats iron-deficiency anemia by raising the Hb level and replacing iron stores. The reticulocyte count should increase within 1 week of beginning iron therapy, and the Hb should rise by at least 1 g/dL within 1 month. Treatment should continue, in patients who respond, for an additional 2 months to ensure adequate replacement of iron stores. Appropriate dietary counseling is important to prevent recurrence. Importantly, although "multivitamin with iron" formulations may be adequate to meet the recommended daily allowance, these products are not appropriate for treatment of iron deficiency.

For patients who fail to respond or who have recurrent iron deficiency, additional laboratory evaluation is indicated, and referral to a hematologist should be considered. Inadequate response may be related to continued blood loss (eg, heavy menses or occult gastrointestinal bleeding), inflammation, ineffective absorption, or poor adherence to treatment.

In patients with moderate to severe anemia (Hb <8g/dL), immediate referral to a pediatric hematologist may be appropriate, especially for children who are symptomatically anemic (eg, elevated heart or respiratory rate, failure to thrive, fatigue), and hospitalization for further evaluation and management may

be indicated (especially for severe anemia, Hb <5 to 6 g/dL). For those who are clinically stable while awaiting a hematology appointment, simultaneous laboratory evaluation should be obtained at the time empirical iron therapy is begun (4 to 6 mg elemental iron/kg of body weight per day).

It is desirable to use the fewest tests that will accurately reflect iron status. Serum ferritin is a sensitive parameter for the assessment of iron stores in healthy subjects. A low serum ferritin (<15 ng/mL) confirms the diagnosis of iron deficiency. However, because serum ferritin is an acute-phase reactant, it may be elevated in the presence of chronic inflammation, infection, malignancy, or liver disease. Other studies that may be helpful in determining iron status include serum transferrin, serum iron, and iron-binding capacity; however, these assays may be misleading if the patient has recently partaken in an iron-rich meal and are, thus, best obtained in the fasting state. A lead level should be considered, particularly for younger children with iron deficiency because they may be more prone to lead intoxication secondary to the pica associated with iron deficiency.

Additional information on the care and management of children with iron-deficiency anemia can be found in Chapter 279, Iron-Deficiency Anemia.

TOOLS FOR PRACTICE

Engaging Patient and Family

- *Anemia and Your Child* (fact sheet), American Academy of Pediatrics (www.healthychildren.org/English/health-issues/conditions/chronic/Pages/Anemia-and-Your-Child.aspx)
- *Anemia and Your Young Child* (handout), American Academy of Pediatrics (patiented.solutions.aap.org)

Medical Decision Support

- *Globin Gene Server* (Web site), Penn State University (globin.cse.psu.edu)

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Chapter 28

VISION SCREENING

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BURDEN OF ILLNESS

Amblyopia, a permanent uncorrectable vision loss, is a major threat to vision that is preventable when detected in early childhood. During development, the visual cortex must receive focused images from both eyes to learn how to see. Conditions that interfere with the normal visual image during this time, such as strabismus, certain refractive errors, or cataracts, can lead to amblyopia if not identified and corrected. Approximately 3% of preschool-aged children have amblyopia, and up to 10% have vision problems, such as refractive error. The prevalence of refractive error increases with age and affects more than 20% of high school–aged children.

BENEFITS OF SCREENING AND EARLY IDENTIFICATION

The likelihood of successfully treating amblyopia decreases with age. The goal is to detect amblyogenic conditions before 5 years of age. The earlier these conditions are identified and treated, the more likely and the more easily amblyopia can be prevented.

From a public health standpoint, screening for vision problems is readily justified on the following counts:

- Vision problems are common.
- Vision problems pose a threat to children's current and future well-being.
- Vision problems are likely to go undetected without screening.
- Screening tests are available that can identify children who have or are at risk for vision problems.
- Effective treatments for vision problems are readily available, and earlier treatment of amblyopia or conditions that lead to amblyopia is associated with improved treatment outcome.
- Many adolescents have refractive error that is easily correctable but unrecognized. Uncorrected refractive error could interfere with school or other activities that rely on sight.

TOOLS

The goals of vision screening are to identify deficits in vision or conditions that might ultimately threaten vision before they otherwise would be discovered, and to ensure that appropriate diagnostic and therapeutic referrals are made so that conditions threatening vision are ameliorated. To achieve the first goal, the physician and staff must learn the appropriate vision screening techniques and procedures and then apply them systematically in their practice. To achieve the second goal, the physician must structure the primary care encounter so that screening results are

communicated accurately to parents, appropriate referrals are made (when indicated), and proper follow-up is achieved.

Appropriate vision screening techniques and procedures vary to some degree for infants and toddlers (younger than 3 years), preschool children (3 to 5 years), and school-aged children and adolescents. Instrument-based vision screening tests (eg, autorefractors) can be useful in young children who cannot cooperate with traditional vision screening tests. However, neither the American Academy of Pediatrics (AAP) nor the United States Preventive Services Task Force recommends routinely using instrument-based tests for children younger than 3 years of age.

The physician's physical examination provides some of the elements of vision screening, especially in infants and toddlers, but vision is tested more efficiently by ancillary personnel and apart from the physical examination. Children who have developmental disabilities are often at increased risk for vision problems and may require special expertise for assessment. Approaches to screening are discussed in the following sections.

INFANTS AND TODDLERS

Physical Examination

The eyes are first examined as part of the newborn examination and should be assessed subsequently at each health supervision visit. As part of the examination, the eyes should be inspected for any structural abnormalities. The red reflex is evaluated for abnormality or asymmetrical appearance through an ophthalmoscope. After an infant can fixate on an object, generally by 3 months of age, the corneal light reflections should be tested by using a penlight held in midline 12 inches in front of the eye (Hirschberg test). Asymmetry of the light's reflection on the 2 corneas suggests strabismus. The examiner should assess ocular motility by having the child follow a brightly colored object or toy. Information from the cover-uncover test is sometimes difficult for the unskilled person to interpret. This test detects movement of each eye when the other eye is covered and then uncovered. Such movement can suggest either a unilateral visual defect or an ocular muscle weakness in the eye that moves. (See Chapter 214, Amblyopia and Strabismus, for more detailed discussions of the physical examination of the eyes.)

Formal Screening

Formal screening tests are not recommended for children younger than 3 years of age because of lack of data regarding screening in infants and toddlers. Any concern by parents or physicians should prompt referral.

Special Circumstances

Infants whose circumstances or family history place them at special risk for visual problems, such as preterm infants at risk for retinopathy of prematurity, those who have a family history of congenital eye problems, or those who have genetic (eg, trisomy 21) or acquired (eg, cerebral palsy) problems that place their vision at risk, should be referred.

Parents sometimes give a history of asymmetry of the child's eyes when none can be demonstrated at the visit. Because some problems of muscle imbalance occur only when the child is fatigued, the examiner would be wise to pay attention to such a history and refer the patient to a specialist if these complaints are persistent. A family history of amblyopia, a *lazy eye,* or *crossed eyes* confers a higher risk of problems and should prompt consideration of referral.

PRESCHOOL CHILDREN

Physical Examination

Eyes should be inspected and the bilateral red reflex, corneal light reflex, and ocular motility tests should be performed at each health supervision visit.

Formal Screening

Testing for visual acuity should be attempted beginning at age 3 years, and an interpretable result should be achieved by age 4 years. Having a child who is uncooperative or inconsistent in responses return for a repeat test is reasonable. Repeated failure to achieve an interpretable test result may be an indication of a visual problem.

In children 3 to 5 years old, the simpler tests of acuity that do not rely on knowledge of letters are the most acceptable. The Lea chart has become popular because children may have an easier time identifying the 4 symbols (apple, circle, square, and house) on this test than on some of the other tests. In general, these tests are available for testing from a distance of 10 and of 20 feet. At 10 feet, children are less likely to become distracted by other activities in the immediate environment.

Testing for binocular vision (stereoacuity) is not a substitute for assessing visual acuity, but it is a useful adjunct and will sometimes identify a child whose vision problems have been missed on physical examination and acuity testing. Acceptable tests for this age group include the Random Dot E Test and the Stereo Fly Test.

Instrument-based testing is an acceptable alternative to assessing visual acuity.

Special Circumstances

Children at high risk for poor vision, as discussed previously, should be referred if satisfactory results cannot be obtained on screening.

SCHOOL-AGED CHILDREN AND ADOLESCENTS

Physical Examination

Eyes should be inspected and the bilateral red reflex, corneal light reflex, and ocular motility tests should be performed at each health supervision visit.

Formal Screening

Once a child knows the alphabet, the Snellen letters on a wall chart are appropriate for visual acuity screening. For school-aged children and adolescents, vision testing machines that combine acuity testing with

tests of binocular vision are readily accepted and require less office space.

Special Circumstances

School difficulties may be a presenting symptom of visual problems, and all children who have such troubles should have their vision evaluated if this has not been done recently. Although the prevention of amblyopia becomes less of a concern with increasing age, the overall prevalence of vision problems increases steadily over time; therefore, children should continue to be tested at health supervision visits.

PERSONNEL AND EQUIPMENT

Nonprofessional personnel who have a high school education can be trained to administer all of these formal tests. The equipment necessary for most of these tests is readily available from medical supply houses and is inexpensive.

REFERRAL

When strabismus or amblyopia is suspected, the child should be referred to an eye care specialist who is skilled in working with young children.

A child who has a structural abnormality of the eye or its movements, any asymmetry or abnormality of the red reflex, any asymmetry of the corneal reflections, aversion to the occlusion of one eye, or any movement of the eyes on the cover-uncover test should be referred.

Preschool children failing to pass a visual acuity test in either or both eyes at the 20/40 level or who display a 2-line discrepancy between the eyes (eg, 20/20 and 20/40), or who fail a test of binocular vision should be referred. In addition, any child who cannot be tested successfully by age 4 years after repeated attempts should be referred. School-aged children and adolescents who fail to pass at the 20/30 level in either or both eyes should be referred. In addition, children who have developmental disabilities who cannot be tested successfully should be referred.

IMPROVING VISION SCREENING AND ITS OUTCOMES

The primary care practice and clinic settings, because they provide continuity of care, remain ideal places to carry out vision screening. Pediatricians need to screen systematically all of the children whom they see for health supervision visits. They should record and communicate the results of the screening to parents and make sure that follow-up and referral appointments are made and kept. Rates of screening are suboptimal, and many children whose visual testing is abnormal never receive evaluation by an eye care specialist.

Few data are available about the accuracy of vision screening in the primary care setting. As in any screening program, a proportion of children will fail vision screening but have a normal eye evaluation. False-positive tests are a feature of all screening programs and should not discourage practitioners from screening. Vision screening examinations will detect the overwhelming proportion of children who have treatable vision problems; practitioners must ensure that these cases are detected and treated properly.

TOOLS FOR PRACTICE

Engaging Patient and Family

- *Vision Screenings* (fact sheet), American Academy of Pediatrics (www.healthychildren.org/English/health-issues/conditions/eyes/Pages/Vision-Screenings.aspx)
- *Warning Signs of Vision Problems in Children* (fact sheet), American Academy of Pediatrics (www.healthychildren.org/English/health-issues/conditions/eyes/Pages/Warning-Signs-of-Vision-Problems-in-Children.aspx)

Medical Decision Support

- *Screening for Visual Impairment in Children Ages 1-5 Years: Update for the USPSTF* (article), *Pediatrics,* Vol 127, Issue 2; 2011 (pediatrics.aappublications.org/content/127/2/e442)
- *Vision Screening Recommendations* (Web page), American Association for Pediatric Ophthalmology and Strabismus (www.aapos.org/terms/conditions/131)

AAP POLICY

American Academy of Pediatrics Committee on Practice and Ambulatory Medicine and Section on Ophthalmology, American Association of Certified Orthoptists, American Association for Pediatric Ophthalmology and Strabismus, and American Academy of Ophthalmology. Eye examination in infants, children, and young adults by pediatricians. *Pediatrics*. 2003;111:902–907. Reaffirmed May 2007 (pediatrics.aappublications.org/content/111/4/902)

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Chapter 29

SCREENING FOR GENETIC-METABOLIC DISEASES

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INTRODUCTION

The aim of newborn screening is to screen for disorders for which early detection and treatment will improve outcome. Newborn screening began in the 1960s, when dried blood spots were first used to identify infants with a high phenylalanine level who might have phenylketonuria (PKU). Over the subsequent decades, tests for hypothyroidism, hemoglobinopathies, galactosemia, biotinidase deficiency, and other conditions were added. In 2006, a "uniform screening panel" of 29 conditions was recommended, as a minimal list to which all states and programs could aspire. This list includes hypothyroidism; hemoglobinopathies; congenital adrenal hyperplasia; cystic fibrosis; galactosemia; biotinidase deficiency; 22 disorders of amino acid, fatty acid, and organic acid metabolism; and hearing loss (not a blood test). More recent additions include severe combined immune deficiency, critical congenital heart disease (not a blood test), and Pompe disease (approved in 2015). This chapter addresses the metabolic disorders of galactosemia, biotinidase deficiency, and the 22 disorders of intermediary metabolism.

OVERVIEW OF NEWBORN SCREENING

Newborn screening is a public health program run by states. The Association of Public Health Laboratories (APHL) maintains current information on those conditions for which the states conduct screening and contact information for the newborn screening coordinators in each state. This information can be accessed at www.newsteps.org. Because states differ in the conditions included in their newborn screening panel, health care providers must familiarize themselves with their state's newborn screening panel. It is important to note that even though the newborn screening program is for the conditions, the screening itself is for analytes (see "Screening Methods" section later in this chapter). Therefore, this review is structured according to the analytes, and includes a discussion of the conditions screened for using a given analyte.

Screening and Follow-Up

Newborn screening starts with a heel prick to collect blood on a blood spot card. Current guidelines from the Advisory Committee on Heritable Disorders in Newborns and Children state that the sample should be collected after 24 hours of age, and no later than 48 hours of age. Timing of sample collection can be modified for infants who received a transfusion or total parenteral nutrition, or were born outside a hospital (eg, home birth). Hospitals have standardized protocols for sample collection. Extensive guidelines are available through the Clinical and Laboratory Standards Institute and through local state newborn screening laboratories. The American Academy of Pediatrics (AAP) has guidelines for efficiently integrating newborn screening follow-up into the clinic workflow. This includes confirmation of whether newborn screening was done, tracking results, communicating results, and coordinating care with subspecialists.

Rescreening

Results of newborn screening are stratified based on the level and ratio of analytes. In general, the results fall into 3 categories: negative screening result, no follow-up required; positive screening result, repeat newborn screening recommended; positive screening result, urgent evaluation, diagnostic testing, and treatment initiation recommended. Each state newborn screening program has guidelines for stratifying and following up results in each of these categories.

All infants who screen positive should be examined by the primary care provider and the screening result explained to the parents. Box 29-1 is a list of resources that can be given to parents to explain the newborn screening report. Unacceptable specimens include those collected before 24 hours of age and those collected incorrectly; these should be re-collected.

Screening Methods

Newborn screening for metabolic conditions uses measurement of either enzyme activity or analytes. Screening for biotinidase deficiency and galactosemia is performed using enzyme assays. The modern era of newborn screening (the expanded newborn screening panel) for metabolic errors began with the development of methods to analyze many amino acids and acylcarnitines in material extracted from dried blood spots on filter-paper Guthrie cards using tandem mass spectrometry (MS/MS). Work by an advisory panel and expert surveys led to the formulation of a list of 13 amino acids, representing 23 disorders, and 38 acylcarnitines, representing 42 disorders of fatty acid and organic acid metabolism. Although the tests are sometimes described as screens for disorders, they are actually screens for metabolites whose abnormal levels may be caused by a specific metabolic disorder. In addition to the primary metabolites, there are many secondary metabolites whose levels and ratios make the testing more precise; there are also many disorders, not part of the main list of 22, whose presence might be recognized by abnormalities of amino acids, acylcarnitines, or both. Tables detailing the metabolites and their associated disorders can be found in the paper by McHugh and colleagues published in *Genetics in Medicine* in 2011.

BOX 29-1 Resources for Families

- Baby's First Test (www.babysfirsttest.org)
- American College of Obstetricians and Gynecologists newborn screening patient fact sheets (www.acog.org/Patients/FAQs/These-Tests-Could-Save-Your-Babys-Life-Newborn-Screening-Tests)
- American College of Obstetricians and Gynecologists seven things parents want to know about newborn screening (www.acog.org/~/media/Department%20Publications/nbs7Things.pdf)

Diagnostic Testing

Newborn screening is not diagnostic for any condition. The American College of Medical Genetics has published open-access newborn screening action (ACT; ACTion) sheets to guide primary care providers on initial management and follow-up testing. Expertise from the local or regional genetics/metabolic team should always be available. The team will be invaluable for confirming the suspected metabolic problem. Genetic counseling can help families understand the disorder, its causes, and the implications for other family members. False-negative results do occur with newborn screening, as with any other test, for various reasons. When a patient presents with features that suggest one of the inborn errors for which newborn screening has already been performed, it is prudent to conduct the appropriate diagnostic test for that disorder.

Breastfeeding and Special Nutritional Needs

Infants with *most* inborn errors of metabolism, except for severe galactosemia, will tolerate some breastfeeding. Most inborn errors of metabolism will require lifelong dietary limitation of the toxic amino acid intake. This is accomplished by means of restriction of natural proteins, supplementation with special formula devoid of the toxic amino acids, and provision of adequate calories. Patients on special diets typically need regular assessment of intake and nutritional status, which includes serial laboratory testing. When needed, dietary guidance will be provided by a metabolic nutritionist. Laboratory samples for monitoring metabolic status may be obtained at home, at the primary care physician's office, or through the local hospital or pathologist, saving time and trouble for the family.

SPECIFIC SCREENING RESULTS

Low or Absent Biotinidase

Clinical Characteristics

Most infants are asymptomatic at birth. Even untreated infants usually do not become symptomatic until 4 to 5 months of age. However, presentation as early as 2 weeks of age can be seen, usually as a result of stresses such as infection. The delay in onset is caused by transfer of sufficient biotin from the mother to the infant. Symptoms, when present, typically involve the skin, brain, and immune systems. Skin manifestations commonly seen are alopecia, eczema, and dermatitis. Neurologic manifestations include hypotonia, seizures, developmental delays, sensorineural hearing loss, and progressive optic atrophy. Immune dysfunction can present as frequent infections. Associated metabolic acidosis can cause vomiting and hyperpnea. With newborn screening and early treatment initiation, biotinidase-deficient patients should remain asymptomatic for life. Newborn screening for biotinidase deficiency is not universal outside the United States and must be considered in the differential diagnosis for intractable dermatitis or a seizure disorder with associated dermatologic involvement. (For further information on biotinidase deficiency, see Chapter 106, Specific Congenital Metabolic Diseases.)

Pathophysiology

Biotin is a B-complex vitamin (B7) that functions as a prosthetic group in all 5 human carboxylase enzymes: pyruvate carboxylase, propionyl-coenzyme A (CoA) carboxylase, 3-methylcrotonyl-CoA carboxylase, and acetyl-CoA carboxylase 1 and 2. These 5 carboxylases play important roles in gluconeogenesis, odd chain fatty acid and gluconeogenic amino acid catabolism, leucine catabolism, and fatty acid synthesis. Major sources of biotin are dietary intake and recycled biotin from endogenous proteins. Liberation of biotin from either of these sources requires the biotinidase enzyme. In biotinidase deficiency, the body is unable to recycle adequate biotin, leading to a functional deficiency of 1 or more of the carboxylases.

Newborn Screening and Diagnostic Testing

Newborn screening uses a semiquantitative colorimetric assay to measure biotinidase enzyme activity. If low or absent, diagnostic testing involves a quantitative serum biotinidase enzyme assay, plasma acylcarnitine profile, and urine organic acid analysis. Some symptomatic infants do not exhibit urinary metabolites when they initially become symptomatic, probably because the effects of the enzyme deficiency are first manifested in the brain before they are evident in the periphery. Genetic analysis of the biotinidase *(BTD)* gene is usually conducted to understand the basis of the biotinidase deficiency and estimate its severity. Serum biotin measurement is not a sensitive indicator of biotin deficiency.

Disease Management

Screening-positive infants should be started empirically on 10 mg of oral free biotin daily, while confirmatory tests are being performed. Relying solely on dietary sources of biotin is not recommended as a treatment option. Families should be advised to avoid raw egg white because it contains avidin, a protein that binds strongly to biotin, reducing its free bioavailable form. Cooked eggs are safe, because cooking inactivates avidin. If biotinidase deficiency is not diagnosed until symptoms develop, sensorineural hearing loss, optic atrophy, and developmental delays may not be reversible.

Low Galactose-1-Phosphate Uridyltransferase

Clinical Characteristics

Onset and severity depend on the degree of galactose-1-phosphate uridyltransferase (GALT, sometimes called *Gal-1-PUT* or *UDPGT*) enzyme deficiency. Classic galactosemia, seen with a GALT activity of 0 to 5% of normal, typically manifests 1 to 2 weeks after milk is introduced. Symptoms include poor feeding, poor weight gain, vomiting, diarrhea, and lethargy. Septicemia (especially *Escherichia coli* sepsis) is a common association and can be the presenting feature. Cataracts can develop within a few weeks, or later. Physical examination may reveal jaundice, hepatomegaly, signs of coagulation abnormalities, hypotonia, and bulging fontanelles. Abnormality of liver (mixed conjugated and unconjugated hyperbilirubinemia, elevated aspartate aminotransferase and alanine aminotransferase levels, coagulation abnormalities) and renal (renal tubular acidosis, galactosuria, glucosuria,

aminoaciduria, proteinuria) function may be present. Late manifestations include developmental delays, especially in speech and language development, ataxia, and premature ovarian insufficiency. These late manifestations have no correlation with the degree of dietary control.

Duarte variant galactosemia is seen when the GALT activity is around 25% of normal. This level of enzyme activity is sufficient to prevent the acute catastrophic consequences of severe GALT deficiency. (For further discussion of galactosemia, see Chapter 106, Specific Congenital Metabolic Diseases.)

Pathophysiology

Lactose, the carbohydrate source in essentially all mammalian milk, is a disaccharide of glucose and galactose. Lactose is broken down into glucose and galactose by the intestinal enzyme lactase. The conversion of galactose to glucose requires 3 enzymes, 1 of them being GALT. Galactokinase deficiency, a rare cause of cataracts, will not be identified on GALT screening, nor will epimerase deficiency.

Newborn Screening and Diagnostic Testing

Newborn screening for galactosemia typically uses the Beutler fluorometric assay to measure the GALT enzyme activity in the dried blood spot on filter paper. If low, diagnostic testing involves measuring the level of galactose-1-phosphate (substrate for GALT) in erythrocytes, and the level of GALT activity. Molecular DNA assay is the next step. Some states use a total galactose assay for newborn screening in an effort to better screen for other disorders of galactose metabolism besides classic galactosemia.

Disease Management

The mainstay of management is a galactose-free diet. This is achieved by replacing human and cow milk with soy milk. If there is significant liver disease at the time of diagnosis, an elemental formula with medium-chain triglycerides may be used transiently. Liver biopsy is rarely needed.

Infants with classic galactosemia can become symptomatic before results of the newborn screening test are reported. Therefore, galactose should be excluded from the diet immediately if clinically suspected, and if the newborn screening result is positive. Dietary treatment typically leads to rapid and complete recovery. Liver and renal dysfunction usually resolve in 1 to 2 weeks. Cataracts, if present, may resolve slowly. Unfortunately, dietary treatment does not alter the course of the late manifestations mentioned earlier in the Clinical Characteristics section. Girls need to be monitored closely in late childhood and adolescence for signs of primary/secondary amenorrhea, because those with ovarian insufficiency can benefit from hormone replacement therapy.

There is no universal agreement on dietary management for infants with Duarte variant galactosemia because the data on long-term neurodevelopmental outcomes are currently conflicting. Some authorities advocate a galactose-free diet in the first year after birth, followed by a galactose challenge with measurement of erythrocyte galactose-1-phosphate level. If this level is higher than 1 mg/dL, galactose restriction is continued. The challenge is repeated every 6 months until galactose-1-phosphate level stabilize at less than 1 mg/dL (.06 mmol/L), at which point galactose restriction is permanently lifted. Other authorities advocate no dietary restrictions from the start. Duarte variant galactosemia does not cause premature ovarian insufficiency.

Results Suggesting Amino Acid Disorders

Table 29-1 summarizes the analytes screened for and the follow-up diagnostic testing for the amino acid disorders covered by newborn screening.

Table 29-1 Amino Acid Disorders

ELEVATED ANALYTE ON NEWBORN SCREEN	POSSIBLE DISORDERS	DIAGNOSTIC TESTING
Phenylalanine, phenylalanine-tyrosine ratio	**PKU,** hyperphenylalaninemia, BH4 deficiency, DHPR deficiency	Plasma amino acid profile, PAH genotyping, urine pterin testing
Leucine, isoleucine (and hydroxyproline, which shares the same atomic mass)	**MSUD,** hydroxyprolinemia	Plasma amino acid profile, urine organic acid analysis
Methionine	**Homocysteinuria (CBS deficiency),** MAT I/III deficiency, GNMT deficiency, AdoHcy hydrolase deficiency, tyrosinemia, liver disease/injury	Plasma amino acid profile, plasma total homocysteine, plasma vitamin B_{12} level, urine organic acid analysis
Tyrosine, succinylacetone	Tyrosinemia (TAT deficiency, 4-HPPD deficiency), liver disease/injury	Plasma amino acid profile, urine organic acid analysis
Succinylacetone	**Tyrosinemia type I (FAH deficiency)**	
Citrulline	**Citrullinemia type I,** citrulinemia type II (citrin deficiency) **argininosuccinic acidemia**	Plasma ammonia level, plasma amino acid profile, urine organic acid analysis

AdoHcy, S-adenosylhomocysteine; *BH4*, tetrahydrobiopterin; *CBS*, cystathionine beta-synthase; *DHPR*, dihydroteridine reductase; *FAH*, fumarylacetoacetate hydrolase; *GNMT*, glycine N-methyl transferase; *4-HPPD*, 4-hydroxyphenylpyruvate dioxygenase; *MAT I/III*, methionine adenosyl transferase isoenzymes I/III; *MSUD*, maple syrup urine disease; *PAH*, phenylalanine hydroxylase; *PKU*, phenylketonuria; *TAT*, tyrosine aminotransferase.
Disorders targeted in the uniform screening panel are in **bold.**

Elevated Phenylalanine With Low Tyrosine on Newborn Screening

PHENYLKETONURIA

Clinical Characteristics. Based on the severity of enzyme deficiency, PKU is classified as classic PKU in infants with complete deficiency, or hyperphenylalaninemia in infants with partial deficiency. Untreated classic PKU results in global developmental delays, intellectual disability, and seizures. But with treatment, classic PKU can be clinically silent or manifest only subtle neuropsychiatric features (slowing of executive functioning, attention-deficit/hyperactivity disorder, depression, and anxiety).

Pathophysiology. Phenylketonuria is caused by deficiency of the enzyme phenylalanine hydroxylase (PAH). PAH oxidizes phenylalanine into tyrosine. Phenylalanine is an essential amino acid. In infants, one-third to one-half of dietary phenylaninine is used directly for incorporation into growing proteins. In adults, only 5% to 10% of dietary phenylalanine is incorporated into protein. The rest is converted to tyrosine. Tyrosine in turn acts as the substrate for the synthesis of the monoamine neurotransmitters (dopamine, epinephrine, and norepinephrine) and melanin. PAH deficiency leads to toxic accumulation of phenylalanine and relative tyrosine deficiency. High phenylalanine levels are directly neurotoxic. In addition, relative tyrosine deficiency leads to reduced synthesis of monoamine neurotransmitters. Excess phenylalanine is metabolized through minor pathways, producing phenylacetate, phenylpyruvate, phenethylamine, and phenylacetylglutamate) which are excreted in the urine. Phenylpyruvate is a phenylketone.

Newborn Screening and Diagnostic Testing. An elevated phenylalanine and phenylalanine-tyrosine ratio on the newborn screen using MS/MS is reported as positive. Elevations are categorized as either mild to moderate or severe. Mild to moderate elevations require repeat newborn screening before diagnostic testing is considered. Diagnostic testing involves plasma amino acid profile. Molecular DNA assay is the next step, because direct enzyme assay requires a liver biopsy.

Disease Management. The normal blood phenylalanine level is 1–2 mg/dL (60–120 mcmo/L). No treatment is needed if the blood level is less than 6 mg/dL (363 mcmo/L). Restriction of dietary phenylalanine is the mainstay of treatment if phenylalanine levels are higher than. The goal is to achieve a plasma phenylalanine level of 2–6 mg/dL (120–263 mcmo/L). Restricting phenylalanine intake to the amount tolerated severely restricts total protein intake, so special metabolic formulas and foods that provide extra tyrosine without phenylalanine must be used. Infants with severe PAH deficiency may tolerate only 250 to 300 mg/d. Nutritional guidelines and recommendations were recently published by a collaborative of the Genetics Metabolic Dieticians International, Southeast Regional Genetics, and National Institutes of Health PKU scientific review committee and by the American College of Medical Genetics and Genomics.

Tetrahydrobiopterin (BH4) is a natural cofactor for PAH. Sapropterin dihydrochloride (synthetic tetrahydrobiopterin, BH4) is an adjunct to diet modifications. Any residual enzyme activity can boost the PAH enzyme activity and increase phenylalanine tolerance. Most responders welcome this addition because it allows them to eat more regular popular protein foods. The brain's exposure to excess phenylalanine (or a high ratio of phenylalanine to tyrosine) is the basis of damage. Because several amino acids share the same transport system across the blood-brain barrier, supplementation with a group of large neutral amino acids may offer some protection by competing for transport. Experimental therapies being investigated include the oral use of an enzyme to convert dietary phenylalanine to a less toxic product (polyethyleneglycol-conjugated phenylalanine ammonia lyase [PEG-PAL]; ClinicalTrials.gov Identifier:NCT01819727).

Phenylketonuria and several other problems can occur together if there is a problem with BH4 metabolism. In addition to PAH, tyrosine hydroxylase and tryptophan hydroxylase also require BH4. These enzymes are necessary for the production of dopamine, norepinephrine, and serotonin. Infants with "malignant hyperphenylalaninemia" are identified by increased phenylalanine on newborn screening, but treating only the PKU component will not prevent brain damage. So after the newborn screening result (high phenylalanine) is confirmed, blood testing is performed for the enzyme dihydropteridine reductase and analysis of urine for pterin derivatives. Treatment of malignant hyperphenylalaninemia involves restriction of phenylalanine, supplementation with sapropterin dihydrochloride, tyrosine, the neurotransmitter precursors L-dopa and 5-hydroxytryptophan, and frequent monitoring. (For further discussion of PKU, see Chapter 106, Specific Congenital Metabolic Diseases.)

MATERNAL PHENYLKETONURIA. The severity of PKU has been greatly reduced with diet modifications and other therapies, so girls with PKU now grow up and wish to start families of their own. This poses a challenge for pediatricians working with adolescents, and physicians in family medicine/internal medicine/obstetrics and gynecology working with adult women with PKU. Poorly controlled maternal PKU is teratogenic, and will result in a spectrum of developmental anomalies called the *maternal PKU (MPKU) syndrome*. The features include microcephaly, intrauterine growth restriction, congenital heart defects, and severe intellectual disability. To avoid this outcome, the mother's phenylalanine level should be less than 6 mg/dL (363 mcmol/L) before conception and during the pregnancy. Frequent monitoring is required. Fetal echocardiography should be considered at 20 to 22 weeks of gestation. Breastfeeding by mothers with PKU is safe, unless the infant also has PAH deficiency.

Elevated Leucine Plus Isoleucine (Xle) on Newborn Screening

MAPLE SYRUP URINE DISEASE

Clinical Characteristics. The age at onset and severity depend on the degree of branched-chain ketoacid dehydrogenase (BCKD) enzyme complex deficiency. Clinical groups include neonatal "classic," intermediate, intermittent, thiamine-responsive, and E3-deficient forms. Encephalopathy is the main clinical manifestation, with elevated leucine thought to be the primary neurotoxin. The neonate with the classic form of maple syrup

urine disease (MSUD) will present with encephalopathy that can progress to cerebral edema and herniation. Most infants with severe MSUD will have some degree of permanent intellectual disability. Prompt newborn screening is followed by a very narrow window of only a few days to confirm the diagnosis and initiate treatment. This rapid course demands prompt action for follow-up evaluation and testing by the metabolic specialist in partnership with the primary care physician.

Pathophysiology. Maple syrup urine disease is caused by a deficiency of the BCKD enzyme complex. BCKD complex is a heteropentamer of 3 catalytic (E1, E2, and E3) and 2 regulatory (kinase and phosphorylase) subunits. BCKD complex plays a central role in the catabolism of branched-chain amino acids (BCAAs)—leucine, isoleucine, and valine. BCAA catabolism provides substrates for multiple pathways, including gluconeogenesis, lipogenesis, and ketogenesis. Deficiency of this multienzyme complex secondary to a deficiency of any of its subunits leads to accumulation of BCAAs and their derivative branched-chain ketoacids.

The BCKD enzyme complex has several subunits that are assembled together. Defects in all subunits are recessively determined. BCKD complex shares some of its components with pyruvate and α-ketoglutarate dehydrogenase complexes. Thiamine as thiamine pyrophosphate (thiamine diphosphate) is a cofactor in all of them.

The intermediate and intermittent forms are less severe and often involve mutations in the E2 subunit, which may be responsive to thiamine supplementation. Mutations in E3 subunit are always severe; this is because E3 is a part of not only the BCKD complex, but also the pyruvate dehydrogenase and alpha-ketoglutarate enzyme complexes and the glycine cleavage system. One would thus expect more severe metabolic derangements.

Newborn Screening and Diagnostic Testing. An elevated total level of leucine and isoleucine (which have the same molecular weight, so are sometimes listed as Xle) on the newborn screen is reported as positive. Diagnostic testing involves plasma amino acid profile and urine organic acid analysis. The BCAAs and their ketoacids are seen to be elevated. The markers with the highest sensitivity for the diagnosis of MSUD are elevated amino acid allo-isoleucine levels and an increased leucine-alanine ratio.

Disease Management. The mainstay of management is dietary restriction of BCAA, while providing adequate amounts of the other amino acids and other nutrients for normal growth and development. This typically involves a high-calorie BCAA-free formula, in addition to a dietary source of whole protein (ie, standard infant formula or breast milk). Because leucine is the most toxic amino acid of the 3, its intake must be rigorously restricted. Sometimes it is necessary to supplement with isoleucine and/or valine, in addition to what is present in the (restricted) natural protein source, to provide enough of those nutrients. Recommendations from the Genetic Metabolic Dietitians International are now available.

Metabolic decompensations are typically triggered by infection, fasting, and dietary indiscretions. It is essential to recognize an impending acute crisis early. Early symptoms include poor feeding, vomiting, and fever. Dinitrophenylhydrazine testing of urine allows home detection of increasing BCAAs, which in turn, allows early initiation of a "sick day" management protocol. Altered level of consciousness and cerebral edema are a significant risk during episodes of illness with MSUD, so careful monitoring is essential. Rapid treatment of increased intracranial pressure may prevent herniation.

Early intervention significantly reduces neuropsychological deterioration over the long term. If the disease is poorly controlled despite good dietary management, liver transplantation is an option. Transplantation cannot reverse existing brain damage, but it will prevent overwhelming metabolic decompensation and further damage.

Successful management of MSUD has been reported during pregnancy and lactation. The metabolic shifts that occur during pregnancy may be rapid, and may be complicated by the nausea, vomiting, and poor intake that occur in many pregnancies. These principles apply to many inborn metabolic errors. (For further discussion of MSUD, see Chapter 106, Specific Congenital Metabolic Diseases.)

Elevated Methionine on Newborn Screening

HOMOCYSTINURIA AND OTHER DISORDERS OF TRANSULFURATION AND TRANSMETHYLATION. Methionine is the screening marker for cystathionine β-synthase (CBS) deficiency, the most prominent cause of homocystinuria. However, elevated methionine can be associated with other conditions listed in Table 29-1.

Clinical Characteristics. Four major organ systems are involved in CBS deficiency: eye (dislocated lens, myopia, glaucoma), bones (osteoporosis, lengthening of the long bones, scoliosis, high arched palate, pes cavus, widened metaphyses with spicules, long slender fingers, pectus deformities), central nervous system (intellectual disability, psychiatric disorders, seizures, dystonia), and vascular (thrombus formation and thromboembolism). Some infants respond to supplementation with pyridoxine (the precursor of pyridoxal-5′-phosphate, the cofactor for CBS). Those who do respond to pyridoxine supplementation typically are older at onset of symptoms and have a less severe phenotype. Age at onset and severity are variable, even within the same family. Thromboembolism has been reported as early as infancy, but most clinical features develop during later infancy to adolescence.

Pathophysiology. Homocysteine is an intermediate in the transulfuration pathway and the closely linked transmethylation pathway. In the transulfuration pathway, homocysteine condenses with serine to form cystathione, using the enzyme CBS. α-ketoglutarate is then cleaved away, leaving cysteine, containing the transferred sulfur. CBS deficiency is the basis of the best-known form of homocysteinuria.

Homocysteine can be methylated to methionine by 2 separate processes. One process uses 5-methyltetrahydrofolate and a vitamin B_{12} cofactor, methylcobalamin. After giving up its methyl group, the folate must be regenerated using methylene tetrahydrofolate reductase (MTHFR). Defects in the first steps of the vitamin B_{12} pathway will lead to impaired synthesis of methionine

and accumulation of methylmalonic acid ("combined deficiency"). The second process of methionine synthesis involves using betaine as a donor, acting through betaine-homocysteine methyltransferase.

Methionine accepts the adenosine moiety from adenosine triphosphate to form S-adenosylmethionine (SAM), a reaction catalyzed by methionine adenosyltransferase isoenzymes I and III (MAT I/III) in the liver. SAM is a versatile methyl donor, taking part in many different reactions. Upon losing its methyl group, SAM becomes S-adenosylhomocysteine (SAH), which is hydrolyzed to form adenosine and homocysteine. Homocysteine can be remethylated to regenerate methionine, completing the methionine cycle.

The risk for thrombus formation and thromboembolism with homocystinuria is thought to be secondary to its effects on vascular endothelial wall and platelet function.

Newborn Screening and Diagnostic Testing. Elevation of methionine on the newborn screen is reported as positive. (Methionine may also be elevated in patients with tyrosinemia or other forms of liver disease.) Homocysteine is not directly measured because most of it is bound to protein. If newborn screening result is positive for hypermethioninemia, diagnostic testing includes plasma amino acid profile, plasma total homocysteine, vitamin B_{12} levels, and urine organic acid analysis. (Amino acid analysis measures only *free* homocysteine; *total* homocysteine is measured using a different technique, and must be specifically requested. Total homocysteine is commonly measured in patients with coronary artery disease or thrombosis.) CBS deficiency will have both hypermethioninemia and hyperhomocystinemia. Enzyme or molecular DNA assay is the next step. It is important to note that newborn screening will miss most pyridoxine-responsive infants who have CBS deficiency. Therefore, clinical manifestations suggestive of CBS deficiency should trigger an evaluation even if the newborn screening result is normal. Low methionine with elevated homocysteine should direct the physician toward disorders of transmethylation (MTHFR and cobalamin complementation groups C-G deficiencies).

(A word about names: Homocyste*i*ne and cyste*i*ne have a terminal sulfhydryl group [-SH]. If a dimer is formed, with a bond between the 2 sulfurs [disulfide bond], the result is homocyst*i*ne, cyst*i*ne, or a mixed disulfide. The disorder is called *homocystinuria*; homocysteine is the amino acid measured.)

Disease Management. The first step in the management of CBS deficiency is to ascertain if the infant is responsive to pyridoxine supplementation. Pyridoxine responsiveness is best ascertained by a trial. There is no standard dosing or duration for a pyridoxine trial, which will probably be done by the geneticist. If responsive, pyridoxine supplementation alone is sufficient treatment. If the patient is not responsive to pyridoxine, however, dietary methionine restriction and supplementation with L-cystine and betaine are recommended. Methionine restriction and L-cystine supplementation have been shown to prevent intellectual disability, lens dislocation, and bony changes. Betaine has been shown to reduce the incidence of thromboembolic events. Anticoagulant therapy has mixed results. If an infant with CBS deficiency needs to undergo surgery, the risk of thromboembolic events can be reduced by good metabolic control and hydration perioperatively.

MATERNAL CBS DEFICIENCY. Hyperhomocysteinemia, resulting from any cause, is associated with an increased risk of preeclampsia. Women with CBS deficiency have an increased risk of thromboembolic events at baseline, which is further increased during the postpartum period. Successful pregnancy outcomes have been reported with good metabolic control, which includes dietary methionine restriction, folate supplementation, and betaine for homocysteine reduction.

Elevated Tyrosine with Normal Phenylalanine on Newborn Screening

TYROSINEMIA. Three separate conditions may be identified: fumarylacetoacetate hydrolase (FAH) deficiency, tyrosine aminotransferase (TAT) deficiency, and transient tyrosinemia of the newborn.

Clinical Characteristics. Fumarylacetoacetate hydrolase deficiency is also called *tyrosinemia type I* or *hepatorenal tyrosinemia*. The onset of biochemical changes typically occurs in the neonatal period or infancy. It can be lethal if untreated. This disorder involves hepatic, renal, and peripheral nerve pathologies. Hepatic involvement is initially biochemical in nature, with elevated transaminases, and coagulation abnormalities (elevated prothrombin time/partial thromboplastin time) that are unresponsive to vitamin K administration. The infants can subsequently develop bleeding, hepatomegaly, and cirrhosis. Renal manifestations include glomerular and tubular injury, with excessive renal loss of glucose, phosphate, amino acids, and bicarbonate (renal Fanconi syndrome). This can lead to vitamin D–unresponsive rickets, nephromegaly, and failure to thrive. The hepatic disease can lead to hepatocellular carcinoma in childhood. (Tyrosinemia type I is one of the rare metabolic disorders that can cause malignancy.)

The mechanism behind the hepatic and renal involvement is not known. Peripheral neuropathy is thought to result from a direct toxic effect of elevated δ-aminolevalunic acid (ALA), secondary to competitive inhibition of ALA dehydratase by succinylacetone. Patients with this condition present with an acute neuropathic pain. This condition is discussed in the section on sick day management principles. Infants with FAH deficiency may have a secondary deficiency of 4-hydroxyphenylpyruvate dioxygenase (4-HPPD), hypothesized to be protective because it reduces the production of toxic downstream metabolites like SUAC. This is the basis of nitisinone (2-[2-nitro-4-trifluoromethylbenzoyl]-1,3-cyclohexanedione; NTBC) therapy discussed in Disease Management in this section. Hypertrophic cardiomyopathy, albeit rare, has been described in this disorder.

Tyrosine aminotransferase deficiency is also called *tyrosinemia type II* or *oculocutaneous tyrosinemia*. Its onset is typically in infancy. Infants can present with painful corneal erosions, circumcorneal injection, lacrimation, and photophobia. These can mimic keratitis resulting from herpes simplex infection, but the lesions

do not take up fluorescein dye. Cutaneous lesions are painful, nonpruritic, hyperkeratotic scaly patches, typically localized to the palmoplantar regions. These lesions are not hyperpigmented, distinguishing them from inflammatory skin conditions. Half the infants have intellectual disability.

Transient tyrosinemia of newborn is caused by immaturity of the 4-HPPD enzyme (and of liver metabolism in general), and therefore, is more prevalent in premature infants or infants receiving high protein formula/intake (>5 g/kg per day). Transient tyrosinemia is principally a biochemical abnormality in an otherwise asymptomatic neonate. The tyrosine level typically peaks by 2 weeks of age and resolves by 1 month or later in premature infants. Before widespread availability of infant formulas to families of limited means, evaporated milk was used as a substitute, leading to excessively high protein intake. Changing to a standard infant formula and vitamin C supplementation would rapidly lower the plasma tyrosine level.

There are some other very rare causes of tyrosine elevation that will not be discussed further in this chapter.

Pathophysiology. Tyrosine is a semiessential amino acid obtained from dietary protein and phenylalanine catabolism. Tyrosine contributes to gluconeogenesis, ketogenesis, synthesis of the monoamine neurotransmitters (dopamine, epinephrine, and norepinephrine), and melanin. Tyrosinemia or elevation of plasma tyrosine is a biochemical finding seen in various conditions. The most common causes are acquired and not inborn errors of metabolism. Transient tyrosinemia of the newborn and tyrosinemia secondary to severe hepatocellular injury are the usual causes. Tyrosinemia from inborn errors of metabolism include deficiencies of any of the 3 enzymes in the main tyrosine catabolic pathway: TAT, 4-HPPD, and FAH.

Newborn Screening and Diagnostic Testing. An elevated tyrosine level on newborn screen is reported as positive. Succinylacetone (SA) is being added to state newborn screening programs to identify infants with tyrosinemia type I (FAH deficiency), because tyrosine alone is unreliable to assess FAH deficiency. Many US state newborn screening laboratories have added succinylacetone to the mass spectrometry target list. Diagnostic testing includes plasma amino acid profile and urine organic acid analysis. In all 3 enzyme deficiencies, tyrosine and its metabolites are elevated in both plasma amino acid profile and urine organic acid analysis. SA is also elevated in FAH deficiency.

Disease Management The first steps are to check the urine organic acids for SA, and to look for acquired causes of hepatocellular injury. The mainstay of treatment for inborn errors of tyrosine metabolism is dietary restriction of tyrosine and phenylalanine by limiting natural protein, and supplementation with a special formula and later medical foods devoid of tyrosine and phenylalanine.

For FAH deficiency, NTBC, which inhibits the enzymatic step before the formation of fumarylacetoacetate is used. This prevents the formation of the most toxic metabolites, including succinylacetone. NTBC has altered the natural course of this disease. It significantly reduces both acute crises and chronic hepatic, renal, and peripheral neuropathic manifestations, and dramatically lowers the risk for hepatocellular carcinoma and neurocognitive delays. Hepatic or combined hepatorenal transplantation can be curative. (See also Chapter 106, Specific Congenital Metabolic Diseases.)

For TAT deficiency, dietary intervention typically resolves the ocular and cutaneous symptoms. A trial of pyridoxine, the cofactor for TAT, can be considered.

MATERNAL TYROSINEMIA TYPE I. Successful pregnancy outcomes, with normal infant growth and development, have been reported in women with tyrosinemia type I. NTBC is not teratogenic and its continued use during the pregnancy is recommended. The newborn screening result in neonates born to mothers with tyrosinemia type I will be positive for elevated tyrosine, secondary to maternal tyrosinemia and NTBC treatment. However, this spontaneously resolves. A urine organic acid analysis will be negative for SA in these infants.

Elevated Citrulline on Newborn Screening

UREA CYCLE DISORDERS. Screening for citrulline, a marker of 2 urea cycle disorders (citrullinemia and argininosuccinic aciduria), is included in the core panel.

Clinical Characteristics. Both conditions affect the urea cycle and share a similar clinical picture. The onset varies from the early neonatal period to late adulthood, depending on the degree of enzyme deficiency. Both conditions lead to hyperammonemia. Hyperammonemia is a respiratory center stimulant, causing tachypnea (and associated respiratory alkalosis), and later, respiratory depression and apnea (and acidosis). Glutamine accumulates as a temporary storage metabolite for excess ammonia. Ammonia may not leave the brain as rapidly as needed, so glutamine can accumulate intracellularly, including in the neurons. This can create an osmotic gradient, leading to diffuse cerebral edema, a bulging fontanelle, rapid increase in head circumference (in neonates), vomiting, lethargy, hypothermia, poor feeding, and eventually coma and death. Hyperammonemia is often confused with sepsis, cerebral trauma, or intracranial bleeding. Some degree of intellectual disability may occur even with good treatment. Infants with argininosuccinic aciduria also may have hair that breaks easily and has a characteristic appearance (on microscopy), with periodic bulging of the hair shafts and rupture of the cortical sheath, called *trichorexis nodosa* or *bamboo hair*. The hair becomes normal with appropriate metabolic treatment.

Neonatal onset seen with severe enzyme deficiency typically occurs after at least 24 hours after birth. Hyperammonemia occurring earlier may be the result of transient hyperammonemia of newborn, pyruvate dehydrogenase deficiency, glutaric acidemia (GA) type II, or sepsis.

Late onset seen in infants with a less severe enzyme deficiency may be triggered by an increase in protein intake. This can occur when an infant is weaned off breast milk or infant formula to cow milk or other nourishment with higher protein content, or later in life during times of increased protein intake. Infection

or other catabolic stressors can also precipitate an episode. The clinical features are similar to those with neonatal onset, but milder and intermittent.

Infants with hyperammonemia or other forms of protein intolerance who are not identified with newborn screening or clinical illness may self-select a low protein diet. This can be an important cue in the history.

Pathophysiology. Urea cycle is the primary pathway for nitrogen waste excretion. It also serves as the major pathway for arginine synthesis and metabolism. Five of the 6 urea cycle enzymes (N-acetylglutamate synthase, carbamoyl phosphate synthetase [CPS], ornithine transcarbamylase [OTC], argininosuccinate synthetase [AS], and argininosuccinate lyase [AL]) are commonly associated with hyperammonemia. The core newborn screening test targets AS deficiency (citrullinemia type I), and AL deficiency (argininosuccinic acidemia). With urea cycle impairment, the body is unable to synthesize sufficient arginine, which then becomes a semiessential amino acid. All 5 urea cycle deficiencies associated with hyperammonemia can be lethal in the neonatal age group, and must be considered in the differential diagnosis of any infant presenting with an encephalopathy after 24 to 48 hours of age. The first test in this situation is to measure the blood ammonia level.

Newborn Screening and Diagnostic Testing. An elevated citrulline on newborn screening is reported as positive. Further testing is required to define the cause of this elevation. Diagnostic testing includes plasma ammonia, plasma amino acid profile, and urine organic acid analysis. Ammonia (and if possible the other 2 tests) must be obtained at the earliest possible opportunity, preferably when the infant is seen again by the primary care physician for urgent evaluation after a positive newborn screening result. Hyperammonemia and plasma amino acid profile with increased glutamine and alanine, and relatively low arginine and ornithine, are present in all 4 urea cycle defects (CPS, OTC, and AS and AL deficiencies). Increased citrulline is only seen in AS and AL deficiencies. When citrulline is significantly elevated, and argininosuccinic acid is not, AS deficiency (citrullinemia type I) is diagnosed. If argininosuccinic acid is also increased, then AL deficiency (argininosuccinic acidemia) is diagnosed.

Disease Management. The mainstay of management is dietary protein restriction, without compromising normal growth and development, by providing a calculated amount of natural protein based on age requirements, and supplementation with a protein-free caloric powder (containing carbohydrates, lipids, minerals, trace elements, and vitamins), and arginine. In addition, infants with AS deficiency are given phenylbutyrate (a precursor of phenylacetate), which acts to enhance excretion of excess nitrogen as phenylacetylglutamine. Phenylbutyrate is not usually required for infants with AL deficiency because they can synthesize argininosuccinate, which removes more waste nitrogen per molecule than citrulline. (Phenylacetate was used before phenylbutyrate, but it has an unpleasant odor and thus not as well tolerated.) Sodium benzoate, which can conjugate with glycine (forming hippurate) to remove excess nitrogen, is sometimes also used. Long-term treatment control and compliance is best assessed by monitoring plasma glutamine (which may be elevated even when ammonia is normal) in the plasma amino acids. Liver transplantation may be considered for severe cases in which metabolic control is difficult to achieve, or if there is a high risk for a catastrophic hyperammonemic event.

Results Suggesting Mitochondrial Fatty Acid Oxidation Disorders

The core newborn screening test is designed to target deficiencies of 4 mitochondrial fatty acid oxidation enzymes: carnitine uptake defect (CUD), medium-chain acyl-CoA dehydrogenase (MCAD), very-long-chain acyl-CoA dehydrogenase (VLCAD), long-chain 3-hydroxyacyl-CoA dehydrogenase (LCHAD), and trifunctional protein (TFP). (See also Chapter 106, Specific Congenital Metabolic Diseases.)

Table 29-2 summarizes the analytes screened for and the follow-up diagnostic testing for the mitochondrial

Table 29-2 Mitochondrial Fatty Acid Oxidation Disorders

ABNORMAL LEVELS OF CARNITINE AND ACYLCARNITINES ON NEWBORN SCREENING	POSSIBLE DISORDERS	DIAGNOSTIC TESTING
Low/absent free carnitine	**CUD,** also called carnitine transporter	Plasma and urine total and free carnitine (and plasma creatinine, for determining the fractional excretion of carnitine)
Elevated C8 +/− C6 and C10	**MCAD**	Plasma acylcarnitine profile, urine organic acid analysis, urine acylglycine analysis
Elevated C14:1	**VLCAD**	Plasma acylcarnitine profile, urine organic acid analysis
Elevated C16-OH +/− C18-OH	**LCHAD, TFP deficiency**	Plasma acylcarnitine profile, urine organic acid analysis

:1, presence of 1 double bond; *C*, carbon length; *CUD*, carnitine uptake defect; *LCHAD*, long-chain 3-hydroxyacyl-CoA dehydrogenase; *MCAD*, medium-chain acyl-CoA dehydrogenase; *OH*, hydroxy fatty acid; *TFP*, trifunctional protein; *VLCAD*, very-long-chain acyl-CoA dehydrogenase.
Disorders targeted in the uniform screening panel are in **bold.**

fatty acid oxidation disorders covered by newborn screening.

Clinical Characteristics

COMMON CLINICAL CHARACTERISTICS. Onset can vary from day 1 of life into adulthood, presenting as episodes of altered mental status, lethargy, seizures, vomiting, dyspnea, tachypnea, apnea, and coma, triggered by catabolic stressors. This presentation is often confused with sepsis. If these episodes are severe, they can cause significant neurodevelopmental delays. Fatty infiltration of the liver can occur, leading to hepatomegaly, liver dysfunction, and the associated complications. This cerebrohepatic involvement is often confused with Reye syndrome. Families can have a history of loss of previous children from unknown causes or sudden infant death syndrome. These are recessive conditions, therefore unscreened siblings of affected children should be tested for the same condition.

Carnitine uptake defect, VLCAD, LCHAD, and TFP deficiencies can present with cardiomyopathy and skeletal myopathy causing exercise intolerance, weakness, soreness, fatigue, or rhabdomyolysis. These are rare in MCAD deficiency.

ADDITIONAL DISEASE-SPECIFIC CLINICAL INFORMATION

CUD. The first peak is between 3 months and 2.5 years of age, presenting with episodes of hypoketotic hypoglycemia. If recurrent, fatty infiltration of major organs can be seen. The second peak is between 1 and 7 years of age, presenting as a cardiomyopathy.

MCAD Deficiency. This is the most common mitochondrial fatty acid oxidation disorder, with wide clinical variability ranging from neonatal death to absence of symptoms into adulthood, even in a family with severe symptoms. Rarely, a parent of a child with MCAD deficiency is also detected to have MCAD deficiency.

VLCAD Deficiency. VLCAD is categorized as 2 distinct phenotypes based on the predominant feature—the early-onset, more severe VLCAD cardiomyopathy (VLCAD-C) and later-onset, less severe VLCAD hypoglycemia/hepatic (VLCAD-H) type. They can be distinguished by enzyme activity and/or mutation analysis.

LCHAD/TFP Deficiency. In addition to the common manifestations discussed before, infants with LCHAD deficiency may have a pigmentary retinopathy and a mixed neuropathy. Hemolytic anemia and thrombocytopenia have also been reported. Women carrying a fetus affected with LCHAD/TFP deficiency may have an acute fatty liver of pregnancy or HELLP (*h*emolysis, *e*levated *l*iver enzymes, *l*ow *p*latelets) syndrome.

Pathophysiology

β-Oxidation of fatty acids takes place in the mitochondria. This pathway is very active in the liver, heart, and skeletal muscles. Fatty acid oxidation is a crucial energy source in times of fasting. This pathway has at least 20 enzymatic steps to carry out the β-oxidation spiral of 4 recurring reactions, with the primary end-product being acetyl-CoA. Acetyl-CoA is used for gluconeogenesis and ketogenesis, and many other processes. In disorders of fatty acid oxidation, paucity of acetyl-CoA leads to hypoketotic hypoglycemia (negative or inappropriately low urine ketones despite hypoglycemia), metabolic acidosis, and hyperammonemia. The unused fatty acids are redirected toward synthesis of triglycerides, phospholipids, and cholesterol esters, which progressively accumulate in different organs including the liver, heart, and skeletal muscles. They may also be conjugated with carnitine.

CUD. As the name suggests, cells are unable to take up carnitine because of a defect in the carnitine transporter protein, OCTN2. Carnitine is required for fatty acid oxidation. In its absence, the cells cannot use fatty acids for energy production despite normal mitochondrial β-oxidation enzymes.

MCAD. This enzyme plays an essential role in the β-oxidation of medium chain fatty acids, 4- to 10-carbon long.

VLCAD. This enzyme plays an essential role in the β-oxidation of long-chain fatty acids, 12- to 22-carbon long.

LCHAD/TFP. These enzymes play an essential role in the β-oxidation of long-chain hydroxy fatty acids, 12- to 16-carbon long. TFP is an enzyme complex made of 2 proteins, one with LCHAD and hydratase activity, the other with thiolase activity. Only LCHAD or all 3 enzyme activities may be impaired.

Note regarding names: Mitochondrial oxidation of long-chain fats, 12- to 22-carbon long, requires an enzyme that, for historical reasons, is called very-long-chain acyl-CoA dehydrogenase (VLCAD). This mitochondrial enzyme is NOT related to the metabolism of very-long-chain fatty acids (>22 carbons), that occurs in the peroxisomes.

Newborn Screening and Diagnostic Testing

The newborn screening tests use MS/MS to evaluate for free carnitine and acylcarnitine species. Each of these 4 screened disorders has a specific pattern of acylcarnitine abnormalities. The patterns flagged positive are as follows:

CUD: Low/absent free carnitine ± low levels of all acylcarnitine species

MCAD deficiency: Elevated C8 ± elevated C6 and C10 acylcarnitine species

VLCAD deficiency: Elevated C14:1 ± other long-chain acylcarnitine species

LCHAD/TFP deficiency: Elevated C16-OH ± C18-OH and other long-chain acylcarnitine species

Diagnostic testing includes a plasma acylcarnitine profile and urine organic acid analysis (plus urine acylglycine analysis if screening is positive for C8 ± C6 and C10). The diagnosis is based on the pattern noted in these tests. Common mutation analysis (MCAD, LCHAD) or gene sequencing assays are the next steps.

Maternal CUD and other mitochondrial fatty acid oxidation disorders: If diagnostic testing for CUD in a screening-positive infant is normal, one must rule out a primary or secondary carnitine deficiency in the mother, including CUD or deficiencies of MCAD, 3-methylcrotonyl-CoA (3-MCC) carboxylase, or glutaryl-CoA dehydrogenase. Mothers in such cases are usually asymptomatic.

Disease Management

The mainstay of daily management is to avoid fasting and to provide adequate calories intravenously during episodes of diminished oral intake.

CUD. Carnitine supplementation is the mainstay of treatment. Very large amounts of carnitine may be required. Carnitine supplementation is very safe. The 2 most common side effects are loose stools and a fishy odor resulting from the production of trimethylamine from carnitine by the gut flora. (There are several strategies to cope with the odor if it occurs.)

MCAD DEFICIENCY. Moderate restriction of dietary fat "heart-healthy diet" and carnitine supplementation is usually used.

LCHAD AND VLCAD DEFICIENCY. Restrict long-chain fat intake, providing adequate amounts of essential long-chain fatty acids. Medium-chain triglyceride formula or supplement will provide fatty acids of medium-chain length, which can be oxidized for energy. In older children, uncooked cornstarch can provide a gradual steady source of complex carbohydrates overnight, thus avoiding the fasting state associated with overnight sleep. Patients with LCHAD/TFP deficiency should undergo regular ophthalmology evaluations because of the risk of retinopathy.

Results Suggesting Organic Acid Disorders

Many clinical and biochemical features of organic acidemias can be explained by the toxic organic acid intermediates that accumulate and the changes they trigger in other biochemical pathways. Hypoglycemia seen in most organic acidemias is caused by disruption of fatty acid oxidation and substrate production for gluconeogenesis because of the sequestration of CoA. Metabolic acidosis is secondary to accumulating organic acid intermediates, especially lactate and ketone bodies. Failure of gluconeogenesis leads the body to shift metabolism toward mitochondrial β-oxidation of fatty acids and ketogenesis for energy generation, resulting in worsening metabolic acidosis and ketosis. In nearly all these disorders, the metabolic block is at a step involving a substrate coupled to coenzyme A; free CoASH may be deficient in other reactions, including production of acetyl-CoA. Deficiency of acetyl-CoA impairs the urea cycle enzyme-N-acetylglutamate synthetase, leading to hyperammonemia. Thus, the majority of the organic acidemias discussed in this chapter will have hyperketotic hypoglycemia, metabolic acidosis, and hyperammonemia presenting as an encephalopathy (poor feeding, vomiting, lethargy, seizures, coma) with signs of metabolic acidosis (hyperpnea).

The primary goal of therapy is to minimize use of the pathway with the deficient enzyme. This is achieved by limiting dietary intake of its precursor, suppressing the production of the substrate from endogenous sources, and enhancing alternative pathways of utilization and detoxification. Dietary limitation must maintain a "balanced" caloric intake for normal growth and development with "substrate-free" formula supplementation. Despite this, the body will still generate some of the targeted substrate endogenously. This will be exacerbated in times of catabolic stress (poor intake, infection, illness, fever, or trauma). Provision of adequate calories suppresses lipolysis, ketogenesis, and gluconeogenesis. Free CoA is recovered from the substrate at the metabolic block using alternative pathways. Carnitine, which is a carrier molecule for fatty acid transfer into the mitochondria, is especially helpful for conjugation with many other substances that have CoA intermediates. Occasionally, a vitamin cofactor for the deficient enzyme can boost its catalytic ability.

Mild, brief illnesses are generally treated by removing the specific substrate from the daily oral intake for 1 to 2 days and providing adequate calories to arrest catabolism. This is often called *sick day formula*. Supplemental carnitine or other detoxifying agents may be given.

If oral treatment is precluded, intravenous glucose (with appropriate electrolytes) and lipids are used. In times of acute crisis when the patient is in a state of hyperketotic hypoglycemia, metabolic acidosis, and hyperammonemia, additional measures must be taken to correct these metabolic derangements. Adequate caloric support is essential. Intravenous L-carnitine can enhance detoxification. Severe hyperammonemia can be treated using hemodialysis or hemofiltration. Patients must be appropriately monitored for blood glucose, ketones, ammonia, and other metabolites, and cerebral perfusion and edema. As with mild illnesses, prolonged complete avoidance of an essential nutrient will lead to ongoing catabolism, so the restricted amino acid(s) must be reintroduced relatively quickly, but gradually. Critically ill patients are usually best treated in an intensive care unit by an experienced team, and with rapid metabolic analysis available on site. (For additional discussion of organic acidemias, see Chapter 106, Specific Congenital Metabolic Diseases.)

Table 29-3 summarizes the analytes screened for and the follow-up diagnostic testing for the organic acid disorders covered by newborn screening.

Elevated C3 (Propionylcarnitine) Species on Newborn Screening

PROPIONIC ACIDEMIA/METHYLMALONIC ACIDEMIA/SOME DISORDERS OF VITAMIN B_{12} METABOLISM

Clinical Characteristics. These disorders share a common metabolic pathway and have overlapping clinical features. The onset of symptoms can range from infancy to adulthood, based on the severity of the enzyme deficiency. Common clinical manifestations include vomiting, poor feeding, lethargy, and tachypnea. In milder cases, self-selected protein avoidance may be seen. Late complications include cognitive delays, seizures, dystonia, and poor growth. Cardiomyopathy can be seen later in life with propionic acidemia and can be the presenting feature. Chronic renal disease and failure frequently occur in methylmalonic acidemia. Some disorders of vitamin B_{12} metabolism present similar to methylmalonic acidemia. In addition, infants with some vitamin B_{12} metabolism disorders have homocysteinuria, which puts them at an increased risk for thrombosis and retinopathy

Table 29-3 Organic Acid Disorders

ELEVATED ACYLCARNITINE ANALYTES ON NEWBORN SCREENING	POSSIBLE DISORDERS	DIAGNOSTIC TESTING
C3 (propionylcarnitine)	**Propionyl-CoA carboxylase deficiency (propionic acidemia), methylmalonyl-CoA mutase deficiency (methylmalonic acidemia), cobalamin metabolism disorders**, maternal vitamin B_{12} deficiency	Plasma acylcarnitine, profile, total plasma homocysteine, urine organic acid analysis
C5	**Isovaleryl-CoA dehydrogenase deficiency (isovaleric acidemia),** antibiotics containing pivalic acid	Plasma acylcarnitine profile, urine organic acid analysis, urine acylglycine analysis
C5-DC (glutarylcarnitine)	**Glutaryl-CoA dehydrogenase deficiency (glutaric acidemia type I)**	Plasma acylcarnitine profile, urine organic acid analysis, urine acylglycine analysis
C5-OH	**3-MCCC deficiency, HMG-CoA lyase deficiency, multiple carboxylase (holocarboxylase synthetase) deficiency,** biotinidase deficiency, **mitochondrial acetoacetyl-CoA carboxylase (branched chain keto-thiolase) deficiency**	Plasma acylcarnitine profile, urine organic acid analysis

3-MCCC, 3-methylcrotonyl-CoA carboxylase; *C*, carbon length; *CoA*, coenzyme A; *DC*, dicarboxylic; *HMG-CoA*, 3-hydroxy-3-methylglutaryl-CoA lyase; *OH*, hydroxy.
Disorders targeted in the uniform screening panel are in **bold.**

secondary to a yet unidentified mechanism. These disorders were called *forms of ketotic hyperglycinemia* caused by significant elevation of plasma and urine glycine, until the individual enzyme defects were discovered. These disorders are unrelated to nonketotic hyperglycinemia, a disorder of glycine cleavage.

Pathophysiology. Propionyl-CoA is the main source of methylmalonyl-CoA. Their disorders share a common metabolic pathway and overlapping clinical features. (The CoA forms are intracellular. The free acids, propionic and methylmalonic, are found in body fluids and urine.) Roughly half the total body propionate is generated during catabolism of 4 essential amino acids (isoleucine, valine, methionine, and threonine), 25% from odd-chain fatty acid and cholesterol metabolism, and the remaining 25% from gut microbial metabolism. Propionyl-CoA is metabolized to D-methylmalonyl-CoA by propionyl-CoA-carboxylase, a biotin-dependent enzyme. D-methylmalonyl-CoA is racemized to L-methylmalonyl CoA. Methylmalonyl-CoA is rearranged by methylmalonyl-CoA mutase, an adenosylcobalamin-dependent enzyme, to succinyl-CoA, a Krebs cycle intermediate. Propionyl-CoA is a 3-carbon compound. Therefore, elevation of the C3 acylcarnitine species on newborn screening indicates a possible problem in this metabolic pathway.

Propionic and methylmalonic acidemias have multiple causes. Propionic acidemia can be secondary to a deficiency of either propionyl CoA carboxylase, or its cofactor, biotin, which is made available by the enzyme biotinidase and enzymatically incorporated into the enzyme by holocarboxylase synthase. Similarly, methylmalonic acidemia is a biochemical diagnosis and can be either from a primary deficiency of methylmalonyl-CoA mutase (complete deficiency; mut0; partial deficiency: mut–), or a deficiency of its cofactor, adenosylcobalamin.

Two forms of vitamin B_{12} (cobalamin or Cbl) are used by humans, adenosylcobalamin and methylcobalamin. Vitamin B_{12} is present in the diet. Several specialized proteins are required for digestion, absorption, and transport in the plasma. After being taken up into the cells, the cobalt moiety undergoes several enzymatic reductions. Separate pathways then lead to the 2 final products, adenosylcobalamin and methylcobalamin. Defects in the first shared steps lead to methylmalonic acidemia with homocysteinuria. Defects in the unshared steps of B_{12} metabolism lead to just 1 of these problems. (Defects specific to the methylcobalamin pathway will not elevate propionylcarnitine.) An important cause of cobalamin problems in newborns is primary deficiency of vitamin B_{12} arising from maternal B_{12} deficiency.

Newborn Screening and Diagnostic Testing. Elevation of C3 acylcarnitine species (propionylcarnitine) on newborn screening can indicate propionic or methylmalonic acidemia. Diagnostic testing includes plasma acylcarnitine profile, total homocysteine, and urine organic acid analysis to help differentiate among propionic acidemia, methylmalonic acidemia (mut0, mut–, CblA, CblB deficiency), cobalamin transport, metabolism disorders (CblC, CblD, CbF deficiency), and vitamin B_{12} deficiency (caused by maternal deficiency). All have an elevated C3 species in the acylcarnitine profile. Methylmalonic acidemia will have elevated urinary methylmalonic acid, a metabolite not seen in propionic acidemia. An elevated total

plasma homocysteine strongly suggests a disorder of cobalamin availability, transport, or metabolism. Complementation group analysis, enzyme assays, or mutation analysis are the next steps.

Disease Management. Management of cases of propionic and methylmalonic acidemia involves limiting natural protein to the amount required/tolerated of the toxic amino acids, supplementing with special formula devoid of the toxic amino acids, and providing adequate calories. Carnitine supplementation to replace that lost as propionylcarnitine is essential in propionic acidemia. In methylmalonic acidemia, relatively little carnitine is lost because methylmalonic acid itself is excreted very readily. Chronic alkali therapy is sometimes needed. The gut production of propionate can be reduced with pulsed oral administration of broad-spectrum antibiotics and early treatment of constipation. In addition, infants with cobalamin transport and metabolic defects (CblA and B), usually respond to hydroxycobalamin given by daily injection. Betaine (to enhance production of methionine by the alternative pathway), carnitine, folic acid, and pyridoxine are also used. In infants with frequent metabolic decompensations despite medical management, hepatic or combined hepatorenal transplantation significantly reduces the frequency of metabolic decompensation. Valproate should be avoided because its intermediate, valproyl-CoA, can combine with carnitine and deplete carnitine stores. In addition, all nephrotoxic drugs should be used cautiously in infants with methylmalonic acidemia, because these infants are susceptible to renal failure as a late complication.

Elevated C5 Acylcarnitine Species on Newborn Screening

ISOVALERIC ACIDEMIA

Clinical Characteristics. Onset is typically in the neonatal period with episodes of vomiting, poor feeding, lethargy, metabolic stroke, and coma (encephalopathy), triggered by catabolic stressors. The infant may also have a peculiar odor reminiscent of "sweaty feet" because of the sweat and cerumen during these episodes. Transient pancytopenia caused by bone marrow suppression has been described. Long-term complications include neurocognitive delays and failure to thrive, if untreated. A good neurocognitive outcome is possible for milder cases. Pancreatitis, although rare, has also been reported.

Pathophysiology. Isovaleryl-CoA is the product of the reaction catalyzed by the BCKD complex, the deficiency of which leads to MSUD, as discussed earlier. This in turn acts as a substrate for isovaleryl-CoA dehydrogenase (IVD), which catalyzes its irreversible conversion to 3-methylcrotonyl-CoA. Deficiency of IVD leads to toxic accumulation of isovaleryl-CoA and its organic acid derivatives, leading to isovaleric acidemia. As mentioned under MSUD, BCAA catabolism provides substrates for multiple metabolic pathways, including gluconeogenesis, lipogenesis, and synthesis of nitrogen buffers alanine and glutamine. Interruption of these pathways will have consequences in times of catabolic stress. Unlike MSUD, in which catabolism of all 3 BCAAs is disrupted, IVD deficiency only disrupts leucine catabolism.

Newborn Screening and Diagnostic Testing. An elevated C5 acylcarnitine finding on newborn screening is reported as positive. Newborn screening can detect C5 acylcarnitine species using MS/MS, but cannot distinguish the different C5 isomers seen in other organic acidemias and with certain antibiotic use. Diagnostic testing involves a quantitative plasma acylcarnitine profile, urine organic acid, and urine acylglycine analysis. Enzyme or DNA molecular assays are the next steps. In isovaleric acidemia, a specific mutation, 932C>T, has been described with a milder biochemical phenotype. Infants with at least 1 copy of this mutation tend to be either asymptomatic or have a milder clinical picture.

Disease Management. The mainstay of management is limitation of dietary leucine, which is achieved by restricting natural protein to the amount required/tolerated, supplementation with special formula devoid of leucine, and provision of adequate calories. In addition, carnitine and/or glycine supplementation enhances the excretion of the toxic organic acid intermediates by conjugating them into less toxic compounds. A good neurocognitive outcome is possible in many cases.

MATERNAL ISOVALERIC ACIDEMIA. With good metabolic control using the usual management as during nonpregnant states, successful pregnancy outcomes can be expected.

Elevated C5-DC (Glutarylcarnitine) Acylcarnitine Species on Newborn Screening

GLUTARIC ACIDEMIA TYPE I

Clinical Characteristics. Most infants are normal at birth, except for macrocephaly and occasional nonspecific findings of jitteriness and irritability. Brain magnetic resonance imaging may show macrocephaly, increased fluid over the cerebral hemispheres. The Sylvian fissure may be widely open. Onset of symptoms (provoked by catabolic stressors) is typically between 6 and 18 months of age with vomiting, hypotonia, developmental regression, seizures, dystonia, dyskinesis (facial grimacing, tongue thrusting, fisting, opisthotonus), and coma (encephalopathy). Hepatomegaly might be present. Most infants do not fully recover from these acute episodes. Neurodegenerative changes accumulate over time with each new episode, revealing a pattern of frontotemporal atrophy and striatal degeneration. Despite the progressive neurodegeneration, cognition and intellect are not affected. Acute pancreatitis has also been reported in association with GA I.

Pathophysiology. GA I is caused by a deficiency of glutaryl-CoA dehydrogenase, a mitochondrial enzyme involved in the catabolism of 3 amino acids, lysine, hydroxylysine, and tryptophan. It catalyzes the conversion of glutaryl-CoA to crotonyl-CoA.

Newborn Screening and Diagnostic Testing. An elevated C5-DC (glutarylcarnitine) acylcarnitine on newborn screening using MS/MS is reported as positive. Diagnostic testing involves a quantitative plasma amino

acid profile, urine organic acid, and urine acylglycine analysis, with elevated glutaric and hydroxyglutaric species in infants with this enzyme deficiency. Enzyme and molecular DNA assays are the next steps.

Disease Management. The possibility of neurodegeneration can be reduced with dietary limitation of lysine intake achieved by natural/tolerated level of the toxic amino acids, supplementation with special formula devoid of the toxic amino acids, provision of adequate calories, carnitine supplementation, and aggressive intervention during catabolic stresses (see Sick Day Management section in this chapter).

ISOLATED 3-METHYLCROTONYL-CoA CARBOXYLASE DEFICIENCY

Clinical Characteristics. The onset typically includes an illness in the neonatal period with episodes of vomiting, lethargy, hypotonia, seizures, metabolic stroke, and coma (encephalopathy) triggered by catabolic stressors. Cardiomyopathy has been reported as a presenting feature in some infants. During these episodes, the infant may have a peculiar odor reminiscent of cat urine. Long-term complications include failure to thrive and neurocognitive delays. However, emerging data suggest that less than 10% of infants diagnosed with 3-MCC deficiency actually develop these symptoms.

Pathophysiology. 3-Methylcrotonyl-CoA carboxylase catalyzes the next step in leucine catabolism after dehydrogenation of isovaleryl-CoA to 3-methylcrotonyl-CoA by IVD. 3-MCC converts 3-methylcrotonyl-CoA into 3-methylglutaconyl-CoA. Deficiency of 3-MCC leads to accumulation of 3-MCC-CoA and its related organic acids. 3-MCC is initially synthesized as an apoenzyme requiring incorporation of biotin, catalyzed by the enzyme holocarboxylase synthetase. Thus, isolated 3-MCC deficiency shares biochemical and clinical features with infants with biotinidase and holocarboxylase synthetase (multiple carboxylase) deficiencies.

Newborn Screening and Diagnostic Testing. Elevated 3-hydroxyisovaleryl/2-methyl-3-hydroxybutyrylcarnitine (C5-OH) acylcarnitine is reported as positive. MS/MS detects the C5-OH acylcarnitine species, but cannot distinguish the different C5-OH isomers. Diagnostic/confirmatory testing involves a quantitative plasma acylcarnitine and urine organic acid analysis. Enzyme or molecular DNA analysis is the next step.

Disease Management. Most infants are asymptomatic except during times of stress; therefore, life long dietary protein (leucine) restriction and carnitine and/or glycine supplementation are usually not necessary.

MATERNAL 3-METHYLCROTONYL-COA CARBOXYLASE DEFICIENCY. A positive newborn screening result for 3-MCC deficiency is sometimes caused by maternal enzyme deficiency; mothers with this condition often are asymptomatic.

3-HYDROXY-3-METHYLGLUTARYL-COA LYASE DEFICIENCY

Clinical Characteristics. Onset can be in the neonatal period to late childhood with episodes of vomiting, lethargy, hypotonia, seizures, and coma (acute encephalopathy), triggered by catabolic stressors. Unlike in IVD and 3-MCC deficiencies, ketosis is not prominent in this condition. In fact, deficiency of this enzyme impairs 1 of the sources of acetoacetate used for ketogenesis. The differential diagnosis for nonketotic or hypoketotic hypoglycemia includes HMG-CoA lyase deficiency, acetoacetyl-CoA thiolase deficiency (discussed later in this chapter) and mitochondrial fatty acid oxidation disorders (discussed before). Long-term complications include neurocognitive delays and seizures secondary to leukodystrophic insults during acute episodes. Isolated cases of cardiomyopathy and pancreatitis have been reported.

Pathophysiology. 3-hydroxy-3-methylglutaryl-CoA lyase (HMG-CoA lyase) catalyzes the next step in leucine catabolism after carboxylation by 3-MCC. HMG-CoA lyase converts 3-methylglutaconyl-CoA into acetoacetate and acetyl-CoA, which then feed into ketogenesis and gluconeogenesis via the Krebs cycle. Deficiency of this enzyme leads to accumulation of 3-methylglutaconyl-CoA and its organic acid products, in addition to reduced ketogenesis and gluconeogenesis. As with 3-MCC deficiency, this condition does not present with elevation of leucine and its ketoacid, because the upstream reaction catalyzed by BCKD complex is irreversible.

Newborn Screening and Diagnostic Testing. An elevated C5-OH acylcarnitine on newborn screening is reported as positive. Newborn screening can detect C5-OH acylcarnitine species using MS/MS, but cannot distinguish the different C5-OH isomers. Diagnostic/confirmatory testing involves a quantitative plasma acylcarnitine profile and urine organic acid analysis. Enzyme or molecular DNA analysis is the next step.

Disease Management. The mainstay of management is avoidance of fasting. Dietary restriction of protein but not fat intake is recommended. Carnitine supplementation can be considered. A ketogenic diet is contraindicated.

MULTIPLE CARBOXYLASE DEFICIENCY

Clinical Characteristics. Onset is typically in the first 3 months of age, with poor feeding, hypotonia, lethargy, seizures, and developmental delays. Dermatitis, alopecia, and immune dysfunction with frequent infections can be present.

Pathophysiology. Multiple carboxylase deficiency should be considered in the differential diagnosis for intractable dermatitis or a seizure disorder poorly responsive to anticonvulsants with associated dermatologic involvement. Multiple carboxylase deficiency is actually the deficiency of a single enzyme, holocarboxylase synthetase. The condition is termed *multiple carboxylase deficiency* because holocarboxylase synthetase is essential for the activation of all 5 human carboxylase enzymes: pyruvate carboxylase, propionyl-CoA carboxylase, 3-methylcrotonyl-CoA carboxylase, and acetyl-CoA carboxylase 1 and 2. All these enzymes are initially translated as inactive apoenzymes. Their activation to holoenzymes requires addition of biotin as a prosthetic group, a step facilitated by holocarboxylase synthetase. Therefore, deficiency of holocarboxylase synthetase can lead to deficiency of 1 or more carboxylases, presenting as a multiple carboxylase deficiency.

Newborn Screening and Diagnostic Testing. Elevation of C5-OH acylcarnitine is reported as positive. Newborn screening using MS/MS will detect C5-OH acylcarnitine species, but cannot distinguish among the different C5-OH isomers. Diagnostic testing involves a quantitative plasma acylcarnitine profile and urine organic acid analysis. Gene sequencing for the holocarboxylase synthetase *(HLCS)* gene is typically not required, except in infants who do not respond to standard treatment, including supplemental biotin. These infants might have mutations that affect the enzyme structure in a way that supplementation with biotin, this enzyme's prosthetic group, will not increase the activity of the enzyme.

Disease Management. Infants who are positive on newborn screening or symptomatic must be seen immediately by the pediatrician. All infants with positive results on newborn screening should be started empirically on 10 mg of oral biotin (free, not bound) daily. Although most infants respond to biotin supplementation, occasionally some infants do not. No other treatment is currently available.

MITOCHONDRIAL ACETOACETYL-CoA THIOLASE (BRANCHED-CHAIN KETO-THIOLASE) DEFICIENCY

Clinical Characteristics. Onset is typically in the first 2 years of age, with episodes of vomiting, lethargy, and coma (encephalopathy), triggered by catabolic stressors.

Pathophysiology. Acetoacetyl-CoA thiolase (branched-chain or β-ketothiolase) is involved in the catabolism of the BCAAs isoleucine and ketolysis. It facilitates the conversion of 2-methyl-acetoacetyl-CoA, an intermediate in isoleucine catabolism, into acetyl-CoA and propionyl-CoA, which then feed into gluconeogenesis via the Krebs cycle and ketolysis. Deficiency of this enzyme leads to accumulation of upstream organic acid intermediates and their derivatives. As with 3-MCC and HMG-CoA lyase deficiencies, this condition also does not present with elevation of isoleucine and its derivatives, because the upstream reaction catalyzed by BCKD complex is irreversible.

Newborn Screening and Diagnostic Testing. Elevation of C5-OH acylcarnitine on newborn screening is reported as positive. Newborn screening can detect C5-OH acylcarnitine species using MS/MS, but cannot distinguish the different C5-OH isomers. Diagnostic testing involves a quantitative plasma acylcarnitine profile and urine organic acid analysis. Enzyme or mutation analysis can confirm the diagnosis.

Disease Management. The mainstay of management is to avoid fasting. Dietary restriction of protein, but not fat intake is recommended. Carnitine supplementation can be considered. A ketogenic diet is contraindicated.

SICK DAY MANAGEMENT PRINCIPLES (GENERAL STATEMENTS)

Metabolic decompensations are typically triggered by infection, fasting, and dietary indiscretions. It is essential to recognize an impending acute crisis early. Early symptoms include poor feeding, vomiting, and fever. This brief guide is to familiarize the primary care physician with the general principles. The management usually requires the involvement of a metabolic geneticist and nutritionist.

Phenylketonuria

Anticipate an increase in plasma phenylalanine level during illness. Brief periods of elevated phenylalanine do not have long-term consequences. No urgent dietary changes are necessary.

Maple Syrup Urine Disease

Management includes rapid elimination of accumulating leucine, providing adequate calories to arrest protein breakdown, and controlling brain edema/herniation.

Tyrosinemia Type I

Acute hepatic crisis and acute peripheral neuropathy crisis are the 2 most common presentations. The first step is to limit catabolism by providing nutrition—preferably oral if tolerated, else lavage—in addition to supplemental intravenous glucose and treating the infection. Acute hepatic crisis, as the name implies, is worsening of liver functions and can present as jaundice, ascites, and/or a bleeding disorder, with hepatic encephalopathy as a late sign. Evaluate with liver enzyme studies, coagulation profile, serum α-fetoprotein, and ammonia levels. Elevated α-fetoprotein, bilirubin, and ammonia are markers of severe liver dysfunction, suggesting an increased risk of impending liver failure and hepatic encephalopathy. Management is otherwise supportive. A peripheral neuropathic crisis can present primarily as a painful peripheral neuropathy lasting for up to a week. Occasionally, this is accompanied by autonomic dysfunction (hypertension, tachycardia) and paralysis requiring mechanical ventilation. If abdominal imaging studies are needed, avoid barbiturates for sedation because they can induce/worsen a peripheral neuropathic crisis. Management involves pain control with analgesics and narcotics. Glucose also helps by inhibiting ALA synthetase. These crises can exacerbate the underlying renal syndrome, and therefore close monitoring of electrolytes and their replacement as needed is recommended.

Citrullinemia Type I and Argininosuccinic Acidemia

If the infant is symptomatic (respiratory symptoms and/or encephalopathy), obtain plasma ammonia measurements to assess the degree of hyperammonemia. If significantly elevated, discontinue all protein intake to reduce nitrogen load and initiate intravenous 10% glucose at maintenance. Urgent hemodialysis is the best way to lower the plasma ammonia level, but high-flow hemofiltration has also been used. Hemodialysis should be repeated until plasma ammonia level is down to 3 times the upper reference range. Once ammonia is down to 3-fold normal, treatment with intravenous sodium benzoate and sodium phenylacetate (in patients with citrullinemia) and 10% arginine (in patients with either citrullinemia or argininosuccinic acidemia) in 10% dextrose is the next step. Intravenous ondansetron 0.15 mg/kg during the first 15 minutes of the initial infusion can help with

vomiting. Increased intracranial pressure can be managed with mannitol. Once ammonia levels are near normal, intravenous medications are switched to oral.

Mitochondrial Fatty Acid Oxidation Disorders

The goal is to divert the metabolism away from the affected mitochondrial fatty acid oxidation pathway and provide carnitine as a carrier for excreting accumulating toxic metabolic intermediates. Anticipatory treatment with D10 1/4NS at 1.5 to 2 times maintenance along with carnitine supplementation helps achieve this goal and should be started at the first sign of an illness. The degree of metabolic derangement can be ascertained by checking a basic metabolic panel (glucose, electrolytes, urea), ammonia, uric acid, creatine phosphokinase, lactate, liver function tests, complete blood count, urinalysis (for myoglobinuria), in addition to plasma total and free carnitine, acylcarnitine profile, and urine organic acid analysis (plus urine acylglycine analysis in infants with MCAD deficiency).

Propionic Acidemia/Methylmalonic Acidemia

Plasma electrolytes, blood gases, and ammonia are the most sensitive tests to confirm a state of acute metabolic decompensation. In addition, lactate and a complete blood count will show lactic acidosis and cytopenia (neutropenia or pancytopenia). If abnormal, plasma acylcarnitine profile and urine organic acid analysis and orotic acid should be obtained, but results need not be awaited for initiating treatment. Additional laboratory tests including amylase, lipase, blood culture, and C-reactive protein should be considered, given reports of pancreatitis and neutropenia. Treatment includes discontinuing all protein intake for the first 24 to 48 hours, initiating intravenous fluids with dextrose 10% or higher to prevent catabolism, doubling the daily dose of carnitine, and lastly for hyperammonemia, initiating sodium benzoate and carbamylglutamate or, if severe, continuous hemofiltration. Do not use phenylbutyrate or phenylacetate. Intravenous sodium bicarbonate might be required if the acidosis is not controlled with the aforementioned measures. Consensus management guidelines published in 2014 by Baumgartner and colleagues provide detailed dosing recommendations for glucose, hydroxocobalamin, biotin, sodium benzoate, and sodium phenylbutyrate, L-arginine-HCL, and N-carbamyl-glutamate therapies.

Isovaleric Acidemia

Management includes removing leucine from the diet and increasing total caloric intake by taking simple sugars and leucine-free formula. If the infant is unable to tolerate oral intake, intravenous glucose should be started at 8 mg/kg per minute (with insulin as needed) to maintain euglycemia. Leucine and other amino acids must be reintroduced after 24 hours to avoid protein catabolism. In addition, carnitine and glycine supplementation should be continued to enhance excretion of the accumulating toxic organic acids.

Glutaric Acidemia Type I

Management includes increasing fluid and caloric intake to reverse the catabolic state with glucose (plus insulin if needed to maintain euglycemia), complete removal of all natural protein for 24 to 48 hours, and carnitine supplementation to help excrete accumulating toxic organic acids. Kolker and colleagues have published detailed management guidelines.

3-Methylcrotonyl-CoA Carboxylase Deficiency

Most infants with 3-MCC deficiency do not need long-term dietary modifications. For the few patients who do become asymptomatic during times of catabolic stress, acute management includes increasing total caloric intake, either enterally with simple sugars or parenterally with intravenous glucose to stop further protein catabolism, in addition to carnitine and glycine supplementation to enhance excretion of the accumulating toxic organic acids.

3-Hydroxy-3-Methylglutaryl Coenzyme A Deficiency

Management includes increasing total caloric intake, either enterally with simple sugars or parenterally with intravenous glucose to stop further protein catabolism, in addition to carnitine supplementation.

TOOLS FOR PRACTICE

Engaging Patient and Family

- *7 Things Parents Want to Know About Newborn Screening From Their Child's Health Professional* (booklet), American Academy of Pediatrics (www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/PEHDIC/Documents/Newborn screeningdisorders.pdf)
- *Baby's First Test* (Web site), (www.babysfirsttest.org)
- *Educational Materials* (handouts), California Department of Public Health (www.cdph.ca.gov/programs/nbs/Pages/NBSEducationMaterial.aspx)
- *Newborn Screening* (Web page), American Academy of Pediatrics (www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/PEHDIC/pages/newborn-screening.aspx)
- *Newborn Screening Information* (Web page), National Newborn Screening & Global Resource Center (genes-r-us.uthscsa.edu)

Medical Decision Support

- *Genetics Home Reference* (Web site), National Institutes of Health (ghr.nlm.nih.gov)
- *Newborn Screening Coding and Terminology Guide* (Web site), National Institutes of Health (newborn-screeningcodes.nlm.nih.gov)
- *Newborn Screening Technical Assistance and Evaluation Program (NewSTEPs)* (Web page), Association of Public Health Laboratories (www.aphl.org/aphlprograms/newborn-screening-and-genetics/Pages/NewSTEPs.aspx)

AAP POLICY

American Academy of Pediatrics Committee on Bioethics, Committee on Genetics; American College of Medical Genetics and Genomics Social, Ethical, and Legal Issues

Committee. Ethical and policy issues in genetic testing and screening of children. *Pediatrics*. 2013;131(3): 620–622 (pediatrics.aappublications.org/content/131/3/620)
American Academy of Pediatrics Newborn Screening Authoring Committee. Newborn screening expands: recommendations for pediatricians and medical homes—implications for the system. *Pediatrics*. 2008;121(1):192–218 (pediatrics.aappublications.org/content/121/1/192)

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Chapter 30

USE OF URINALYSIS AND URINE CULTURE IN SCREENING

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INTRODUCTION

Examination of the urine is a simple and efficient office procedure that may diagnose renal, urinary tract, or systemic disorders. Pediatricians should be comfortable performing and interpreting a urinalysis.

Until 2007, the American Academy of Pediatrics (AAP) recommended that all children undergo a dipstick urinalysis at 5 years of age and during adolescence if sexually active. The AAP no longer recommends that children undergo screening dipstick urinalysis. Because multiple large-scale studies of healthy school-aged children have demonstrated the low incidence of chronic kidney disease (CKD) in children, the AAP recommends that a dipstick urinalysis be performed only in patients at higher risk for chronic kidney disease (see following text). Further, the early detection of CKD in asymptomatic children does not seem to alter ultimate disease outcome. In addition, the high rate of false-positive and true-positive results for benign conditions (eg, orthostatic proteinuria) results in additional tests that generate increased costs and anxiety for patients and families. However, the decision to perform routine dipstick urinalysis ultimately rests with the primary care physician.

Dipstick urinalysis clearly is warranted in symptomatic children. The presence of heavy proteinuria (nephrosis or other renal disease), hematuria (glomerulonephritis), glucosuria (diabetes mellitus), or nitrite/leukocyte esterase (urinary tract infection [UTI]) can help the pediatrician diagnose and manage pathologic conditions. Urinalysis may also be valuable in patients who have vague complaints, such as failure to thrive or malaise, because some renal diseases may present with nonspecific symptoms. This chapter outlines the importance of appropriate urine collection for screening dipstick urinalysis, highlights some of the common anomalies detected by dipstick urinalysis, and outlines select patient populations that may benefit from screening dipstick urinalysis.

SAMPLE COLLECTION

The results of any urinalysis depend on proper collection, preservation, and careful examination. Urine should be collected in a clean, dry container. A first morning, midstream, clean-catch specimen is most reliable for this purpose. First morning voided specimens yield the most concentrated urine and are more likely to show formed elements and allow detection of bacteria because of overnight incubation in the bladder. When obtaining a first morning urine sample, it is important that the child empty his bladder the night before the collection is obtained. Upon awakening the following morning, the urine specimen needs to be collected before other daily activities are performed. Ideally, the voided sample should be tested upon waking to ensure sensitivity and specificity of the urinalysis. Preservation methods, such as refrigeration or the use of chemicals, are necessary if the urine is not tested within 1 hour of collection.

If a UTI is suspected, a urine culture should be obtained. In older children, a clean-catch midstream specimen collected in a sterile, covered container is sufficient. The area around the urethral meatus should be cleaned with an antiseptic solution and the first few milliliters of the voided specimen should be discarded before the clean-catch sample is obtained. For infants and small children, suprapubic aspiration or transurethral bladder catheterization is the preferred specimen for documenting a UTI. Cultures of urine specimens collected in a bag applied to the perineum have an unacceptably high false-positive rate (85%). In 2011, the AAP released updated guidelines for the detection and evaluation of UTIs in febrile infants and young children. These guidelines state that the diagnosis of a UTI cannot be established by a culture of urine collected in a bag.

PROTEINURIA

Urine contains small amounts of protein, normally 100 mg/m^2/24 hr. In children, two-thirds of the physiologic urine protein consists of albumin and one-third

represents a mixture of globulin and Tamm-Horsfall protein. Proteinuria is detected readily by the dipstick method. The presence of protein causes a change in the dipstick's reagent indicators that use buffered bromophenol blue or tetrachlorophenol. The binding of protein to the reagent results in changing colors from yellow to blue-green that is proportional to the amount of protein present (from 300 to >1,000 mg/dL). The reagent strips are much more sensitive to albumin than globulins, hemoglobin, or Bence-Jones protein. The small quantity of protein that a healthy individual excretes is not usually detected by this method. The sensitivity of detecting proteinuria with a urine dipstick ranges from 83.9% to 95.1%, and the specificity ranges from 93.8% to 95.5%. False-positive findings can occur in alkaline urine (pH >7.5), in concentrated urine (specific gravity ≥1.015), or in urine contaminated by skin antiseptics such as chlorhexidine or benzalkonium chloride.

Proteinuria can best be categorized as transient, postural, or persistent. Transient proteinuria is defined by the disappearance of urinary protein following 1 or more positive tests. Transient proteinuria accounts for most cases of isolated proteinuria and can result from a mild illness, fever, heavy exercise, stress, or significant heat/cold exposure. It is commonly seen in the setting of evaluation for sports participation, especially if the evaluation occurs directly following practice or heavy exercise.

If a child has evidence of proteinuria on dipstick urinalysis, a first morning urine specimen should be collected to evaluate for postural proteinuria. A urine protein-to-creatinine ratio can be measured from this sample. A ratio greater than 0.2 mg protein/mg creatinine is considered abnormal for children older than 2 years. Up to 60% of children who have evidence of proteinuria on dipstick urinalysis will have postural proteinuria. Postural or orthostatic proteinuria is a benign condition occurring only when a child is in the upright position. Recumbent urine specimens do not have protein, while upright samples contain protein. Postural proteinuria is typically associated with normal blood pressure and normal kidney function.

In a 20-year follow-up study of young men who had persistent orthostatic proteinuria, none developed renal insufficiency, including those who had nonspecific glomerular abnormalities on renal biopsy. Regular follow-up, however, remains important for these children so that changes in the pattern of protein excretion can be evaluated. More than 40% of cases spontaneously resolve within 4 years, and the incidence of identifiable renal disease is 1 child per 1,000 children screened.

Persistent nonpostural proteinuria indicates an underlying renal disease and should be more thoroughly evaluated. Signs and symptoms such as edema, hematuria, polyuria, hypertension, poor weight gain, growth delay, recurrent UTI, or a past history of renal disease may help uncover the cause of proteinuria. A meticulous examination of fresh urinary sediment should precede any additional laboratory evaluation. Please refer to Chapter 183, Proteinuria, for more information on examining urinary sediment and on an approach to the patient with proteinuria.

Yoshikawa and colleagues reported on 53 children who were examined retrospectively after being biopsied for asymptomatic, fixed isolated proteinuria. They found that 47% had significant glomerular changes (focal segmental glomerulosclerosis, IgA nephropathy, mesangial proliferative glomerulonephritis, and membranous glomerulonephritis), which seemed to progress with time to chronic renal impairment. In Silverberg's studies, approximately 9% of children with isolated proteinuria had evidence of scarring. While some children who have proteinuria may have an abnormality that requires no additional management (eg, a hypoplastic kidney), others may have diseases that may improve with treatment (eg, focal glomerulosclerosis or IgA nephropathy). However, most children who have significant renal disease do have other signs and symptoms (eg, hematuria, edema, poor weight gain, or hypertension) that cause them to seek medical care, and thus they can be identified even in the absence of screening programs.

HEMATURIA

Persistent hematuria occurs in about 2% of children and adults in the community. Often, hematuria in children is benign, with unknown etiology and prognosis. Nonetheless, it can be distressing for patients, parents, and physicians. Red blood cells (RBCs) in the urine may originate from any site in the urinary tract. Bleeding may be microscopic or gross. It may be painless or painful. The differential diagnosis for hematuria includes glomerular disorders, UTIs, urethralgia, nephrolithiasis, hypercalciuria/crystalluria, hematologic disorders, drugs, and anatomic anomalies.

Not all discolored urine indicates hematuria. Urine can be discolored by a number of substances. Therefore, the presence of gross blood should be confirmed by dipstick analysis. The urinary dipstick is highly sensitive, reacting to hemoglobin levels as low as 0.015 to 0.062 mg/dL. Depending on the degree of hematuria, the sensitivity of the dipstick for blood is 85% to 100% and the specificity is 86.3% to 99.3%. False-positive test results for blood in the urine may result from the presence of contaminating oxidizing cleansing agents (eg, povidone-iodine or hypochlorite) or microbial peroxidases. False-negative results are caused by the presence of large amounts of a reducing agent, such as ascorbic acid.

A positive dipstick analysis for blood does not discriminate between hemoglobin and myoglobin. Myoglobin can be differentiated from hemoglobin because the plasma remains colorless with increased myoglobin and remains pink-red with hemoglobinemia. Additional tests, such as elevated serum creatinine kinase levels to detect muscle injury, electrophoresis, or ammonium sulphate tests (precipitates hemoglobin but not myoglobin), may also aid in differentiation.

The urine dipstick does not differentiate hemoglobinuria from hematuria or whether the blood originates from the upper or lower urinary tracts. Localizing the source of bleeding facilitates the diagnosis.

Glomerular bleeding (upper tract) is suggested by the presence of RBC casts, proteinuria, brown or tea-colored urine, and dysmorphic RBCs. Conversely, red or pink urine or clots usually indicate lower urinary tract bleeding.

Few children diagnosed with hematuria by large-scale screening programs are found to have significant renal or urologic disease. However, a positive dipstick reaction for blood should be confirmed by the presence of RBCs on microscopic analysis. If there are more than 5 RBCs per high-powered field, then a repeat dipstick for blood should be done in 2 to 3 weeks. Two-thirds of these children will have no hematuria on repeat testing. A positive reaction for blood by dipstick analysis in the absence of proteinuria is typically not associated with renal disease. Asymptomatic children and adolescents with both blood and protein on dipstick analysis are more likely to have renal disease than those with just 1 positive reactant. They may require further evaluation and referral to a nephrologist.

Hematuria persisting for longer than 6 months is likely to be associated with renal disease if the patient has had at least 1 episode of gross hematuria or proteinuria, or has a family history of hematuria in a first-degree relative. The most likely diagnoses in these cases are Alport syndrome (hereditary nephritis), thin basement membrane disease, and IgA nephropathy. In a review of studies of screened symptomless microscopic hematuria, IgA nephropathy was found in 2% to 21% of biopsies, and other glomerular lesions were much less common. The most common nonglomerular finding was asymptomatic UTI (4.8%–6.0%). In other follow-up studies of children referred for isolated hematuria, the most common underlying diagnosis found was hypercalciuria (11%–16%). The presence of hematuria with proteinuria is strongly suggestive of glomerular disease.

In the case of persistent microscopic hematuria, a careful examination of fresh urinary sediment and microscopic analysis should precede any additional laboratory evaluation for asymptomatic children. Most of these children will not have clinically significant disease. Please refer to Chapter 160, Hematuria for further workup and diagnostic evaluation of persistent hematuria.

GLUCOSURIA

Urinary glucose can be detected by glucose oxidase-impregnated dipsticks. Normally, all of the filtered glucose is reabsorbed by the proximal tubules, and glucose is not detectable in the urine when the plasma glucose is less than 180 mg/dL. Glucosuria is seen most commonly when the filtered load of glucose is increased as a result of hyperglycemia in patients with diabetes mellitus. Less often there is a defect in proximal tubular reabsorption that may be selective, as in renal glucosuria, or may be part of a more generalized proximal tubular dysfunction, as in Fanconi syndrome. Measurement of blood glucose differentiates among these conditions. Glucosuria also is seen in the latter stages of tubular destruction of focal segmental glomerulosclerosis. In this condition, the urinalysis usually also shows proteinuria and the urinary sediment may contain renal tubular cells and casts.

Screening for glucosuria reveals a prevalence that is less than 0.1%. Although between 10 and 50 previously undetected cases of diabetes mellitus per 100,000 children could be identified, new-onset diabetes mellitus is much more likely to present with classic symptoms of polyuria, polyphagia, and polydipsia. Cases of renal glucosuria, Fanconi syndrome, and other tubular dysfunction may be rarely identified. Therefore, the cost effectiveness of screening asymptomatic patients for glucosuria is extremely low, and such screening is not recommended.

BACTERIURIA

When evaluating a febrile child with no apparent source for the fever, the physician should assess for the likelihood of a UTI. The overall prevalence of UTI in febrile infants who have no source for their fever is approximately 5%, but it is possible to identify patient populations with a higher or lower likelihood to develop a UTI. The prevalence of UTI among febrile infant girls is more than twice that among febrile boys (relative risk 2.27). The rate of UTI for uncircumcised boys is 4 to 20 times higher than that for circumcised boys, whose rate of UTI is only 0.2% to 0.4%.

As previously mentioned, the method of collection of a urine specimen in children is important for the diagnosis of a UTI. When obtaining a urine specimen, the criteria that are taken into consideration are contamination, technical feasibility of obtaining urine, and invasiveness. Overall, catheterization is the preferred method for urine collection for children who cannot void upon request. Suprapubic bladder aspiration, which is the method that is least likely to be contaminated, may be impractical in some settings. For children who are older than 2 years and who are toilet trained, a midstream urine sample is recommended.

When diagnosing a UTI, physicians should require *both* dipstick urinalysis results that suggest infection (pyuria and/or bacteriuria) and the presence of at least 50,000 colony-forming units per mL of a cultured uropathogen. A dipstick urinalysis cannot substitute for a urine culture but needs to be used in conjunction with a culture. Moreover, an appropriately collected urine specimen is critical, and bagged urine specimens have little clinical value.

The dipstick urinalysis tests that have received the most attention are the biochemical analysis of leukocyte esterase and nitrite. The nitrite test is not a sensitive marker in children, particularly infants, who empty their bladders frequently. Nitrites are extremely specific to bacteriuria with a specificity of 98%, but a sensitivity of only 50%. Leukocyte esterase is much more sensitive (84%), but has a lower specificity of only 78%. When either leukocyte esterase or nitrite is positive, the sensitivity is 88% with a specificity of 93%. When both leukocyte esterase and nitrites are positive, the sensitivity is 72% and the specificity is 96%.

A positive leukocyte esterase test result without the presence of nitrites should be interpreted with caution. Numerous conditions other than UTI can cause a positive leukocyte esterase, including febrile illnesses and inflammatory kidney disease (ie, nephritis). Therefore, the finding of pyuria (white blood cells) by no means confirms that an infection of the urinary tract is present. However, the absence of pyuria in children with true UTIs is rare.

If bacteria are detected in the urine in the absence of pyuria, the physician should consider the diagnosis of asymptomatic bacteriuria. Asymptomatic bacteriuria is often present in school-aged and older girls. The prevalence of asymptomatic bacteriuria in school-aged children is 1% to 2% in girls and 0% to 0.1% in boys. Asymptomatic bacteriuria is defined as growth of more than 10^5 cfu/mL of a single uropathogen in at least 2 consecutive urine specimens in a child who is asymptomatic. Asymptomatic bacteriuria can easily be confused with a true UTI in a febrile infant, but needs to be distinguished because studies suggest that antimicrobial treatment may do more harm than good. The key to distinguishing a true UTI from asymptomatic bacteriuria is the presence of pyuria and active inflammation.

Treatment of asymptomatic bacteriuria may be associated with a greater risk for pyelonephritis, because it may promote the development of more pathogenic and resistant organisms. Furthermore, antibiotic treatment does not prevent further renal scarring once it has occurred, nor does it restore poor renal growth.

Extensive investigations of asymptomatic bacteriuria in schoolgirls have shown that observation does not influence the episodes of symptomatic UTI, renal growth, or glomerular filtration rate in normal or scarred kidneys.

Screening of asymptomatic patients for asymptomatic bacteriuria is not recommended. If asymptomatic bacteriuria is discovered, it should not be treated. Persistent bacteriuria should be pursued with a careful history for renal and urinary tract symptomatology, examination of growth and blood pressure, and possibly a renal ultrasound to determine risk for progressive renal disease (see Chapter 344, Urinary Tract Infections).

TESTING HIGH-RISK PATIENTS

The AAP recommends that a dipstick urinalysis should be performed only in patients at high risk for chronic kidney disease. Many pediatric nephrologists recommend that children with certain medical conditions, including diabetes mellitus, a history of postinfectious glomerulonephritis, acute kidney injury, or a history of hemolytic uremic syndrome or Henoch-Schönlein purpura have a dipstick urinalysis done at every health maintenance visit until several urines are negative. Children with sickle cell disease or trait or a strong family history of renal disease should have a dipstick urinalysis done at each or every other health maintenance visit. An occasional dipstick urinalysis may also be indicated for children with a body mass index greater than 97%, a history of prenatal (or postnatal) hydronephrosis, prematurity (<32 weeks), or a strong family history of kidney stones.

WHEN TO REFER

- Persistent proteinuria (first morning void)
- Gross hematuria of unknown cause
- Persistent hematuria associated with proteinuria or hypertension
- Elevated serum creatinine or proteinuria with glucosuria or history of diabetes
- Recurrent UTIs or history of recurrent pyelonephritis

TOOLS FOR PRACTICE

Engaging Patient and Family

- *Urinalysis and Kidney Disease: What You Need to Know* (handout), National Kidney Foundation (www.kidney.org/sites/default/files/11-10-1815_HBE_PatBro_Urinalysis_v6.pdf)
- *Urinary tract infections* (fact sheet), National Kidney Foundation (www.kidney.org/atoz/content/uti)

Medical Decision Support

- *Pathologic Proteinuria Calculator* (interactive tool), Metro Health (www.metrohealthresearch.org/schelling)
- *Periodicity Schedule* (Web page), American Academy of Pediatrics (www.aap.org/en-us/professional-resources/practice-support/Pages/PeriodicitySchedule.aspx)
- *Screening for Albuminuria in Patients with Diabetes* (app), National Kidney Foundation (www.kidney.org/apps/screening-albuminaria-patients-diabetes)

AAP POLICY

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Health Promotion in Practice

Chapter 31
APPLYING BEHAVIOR CHANGE SCIENCE

Sebastian G. Kaplan, PhD; Robert P. Schwartz, MD

Diseases cannot be managed with medication alone. In many instances, prognosis depends largely on whether the patient's caregivers adopt health behavior changes designed to prevent or effectively treat the child's condition.

As a result, effective communication is a crucial skill for any physician. Often the behavioral component of treatment is a complex set of lifestyle changes, such as new exercise regimens, adoption of behavior management strategies by parents, or frequent finger sticks to assess blood glucose levels. However, even when treating seemingly routine ailments, such as group A streptococcal pharyngitis, the pediatrician engages in communication about patient and caregiver behavior, in this case adherence to antibiotics. How can a pediatrician most effectively engage patients and caregivers in changing health behaviors?

RELATIONSHIP BETWEEN PATIENT-CENTERED CARE AND HEALTH PROMOTION

In 2001, the Institute of Medicine (IOM) published a report titled *Crossing the Quality Chasm: A New Health System for the 21st Century*. To address growing concerns with the US health care system, the IOM proposed 6 aims for improvement, one of which was patient-centered care. The IOM defines *patient-centered care* as "respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions." A similar term used by researchers is *relationship-centered care,* which advocates similar principles as the patient-centered approach but with more emphasis on the collaboration between the patient and physician. The American Academy of Pediatrics (AAP) has also recommended the use of patient-centered communication strategies (eg, motivational interviewing, described in more detail later) for challenging conditions such as pediatric obesity.

Implementing a patient-centered model of health care is easier said than done, in part because of the stark contrast between patient-centeredness and the authoritarian role traditionally found in physician-centered doctor–patient relationships. However, the empirical evidence supporting physician adherence to a patient-centered approach is expanding.

Safran et al found that the variables most predictive of patient adherence to physician advice were the physician's comprehensive or whole-person knowledge of the patient, as well as the patient's trust in his or her physician. Stewart et al examined the effect of patient-centeredness during office visits using a cohort of 39 family physicians and 315 of their patients. Patient-centered communication was correlated with improved patient outcomes (eg, improvements with discomfort, pain, and emotional health), as well as reduced need for diagnostic tests and referrals. Finally, Stewart conducted a review of 21 studies on the effect of physician–patient communication on health outcomes and concluded that most published findings support a direct relationship between effective communication and a number of positive patient health outcomes, including emotional health, symptom resolution, function, physiologic measures, and pain control.

SELF-DETERMINATION THEORY

Why might patient-centered care lead to such robust patient health outcomes? A number of possible theories and models exist. One theory of human motivation, called *self-determination theory* (SDT), differentiates among several types of human motivation rather than focusing on how much motivation a person may have. SDT also considers how each type of motivation predicts certain outcomes, including those pertaining to health and well-being.

A central tenet in SDT is the distinction between autonomous motivation and controlled motivation. Autonomous motivation includes a range of motivation types, from intrinsic, whereby a person experiences a natural inclination toward a particular behavior purely for its inherent satisfactions, to some forms of extrinsic motivation, whereby the person has largely internalized the value of a particular choice as a result of external forces. Controlled motivation, on the other hand, consists of 2 types of extrinsic motivation whereby the primary forces governing a person's actions are either completely external (ie, contingent rewards or punishments) or partially internalized (ie, internal gratification associated with approval from others or avoidance of shame).

The distinction between autonomous and controlled motivation is important in that each type predicts different outcomes. Research has demonstrated that the more an individual is intrinsically motivated, the more likely he or she is to experience improved performance, creativity, self-esteem, and general well-being. Regarding health outcomes, the application of SDT in health care settings has grown as the research supporting the link between autonomously motivated health behavior and positive health outcomes has strengthened.

Williams et al emphasized the importance of physicians being "autonomy supportive" rather than "controlling" in their interactions with patients and patients' families. They reviewed research on the relationship between intrinsic patient motivation, autonomy-supportive physician interaction, and a host of health-related benefits, including engagement in alcoholism treatment, adherence to long-term medication regimens, successful participation in a

weight management program, improved glucose control, and smoking cessation. A relevant caveat to these studies is that they all involved adult populations. Can SDT be applied to the practice of pediatrics, and if so, what strategies can be useful in pediatric settings?

DEVELOPMENTAL PERSPECTIVES ON HEALTH PROMOTION

The practice of pediatrics poses unique challenges that are often absent in other areas of medicine. Beyond analyzing clinical data to arrive at a diagnosis and resulting treatment plan, the pediatrician must use vastly different approaches when working with infants, preteens, or adolescents. Furthermore, engaging the patient's caregivers is frequently a crucial element in both the diagnostic process and communication about treatments. How can physicians apply behavior change science to the range of pediatric clinical situations?

Most research on health behavior change has been conducted with adult populations. As is often the case, a theory first gains empirical support using adult samples, followed by attempts to test the theory with pediatric cohorts. Much of the initial evidence supporting the application of SDT with children and adolescents comes from research in educational settings, in which studies have demonstrated positive relationships between autonomous academic motivation and enhancements in behavioral, cognitive, and affective domains. Furthermore, research has shown that both parents and teachers can effectively support autonomous academic motivation in children and adolescents, which often results in positive educational outcomes. Support for SDT as a model for pediatric health promotion has emerged, primarily in the areas of increasing physical activity.

A school-based intervention using SDT principles was more effective in increasing high school students' intention to exercise and self-reported leisure time physical activity than the control condition. The authors designed the SDT-based intervention to include 4 important components of autonomy-supportive relationships: (1) providing a rationale for exercise; (2) feedback; (3) choice; and (4) acknowledging barriers to becoming more physically active. The control condition included only (1) providing a rationale and (2) feedback. Another study that tested a model grounded in SDT found that adolescents whose motivation to exercise was primarily intrinsic (eg, fitness, enjoyment) positively predicted improved quality of life and exercise behavior compared with adolescents whose motivation was primarily extrinsic (eg, pressure from others, weight control). Other studies explicitly testing SDT-based models with younger patient cohorts have found similarly positive outcomes, such as reduced dropout from an eating disorder inpatient program and increased engagement in substance abuse treatment.

MOTIVATIONAL INTERVIEWING

Given the call to adopt patient-centered care and the science supporting its efficacy, how might a pediatrician engage with patients and caregivers to promote health behavior change? Motivational interviewing (MI), a counseling method that originated as an intervention for alcohol abuse, has gained empirical support for its effectiveness in adults and children. From a relational foundation that is empathic, autonomy supportive, and nonconfrontational, MI seeks to enhance a patient's intrinsic motivation to adopt health behavior changes.

An MI practitioner uses a variety of engagement strategies with patients and caregivers, such as reflective listening, open-ended questions, and affirmations, which establish a collaborative relationship that honors a patient's autonomy. In addition to the patient-centered style, often referred to as the "MI spirit," MI practitioners strategically elicit and reinforce patient "change talk." For instance, if a patient expresses ambivalence about change ("sustain talk"), citing barriers to implementing a specific plan while also mentioning the desire or need to make lifestyles changes, an MI practitioner intentionally chooses to reflect on the desire and need for change expressed in the patient's statements rather than confronting the patient for a lack of progress. The MI practitioner would engage with the patient in such a way that increases the likelihood that the patient makes the necessary argument for and commitment to health behavior change.

Rollnick et al described 3 communication styles evident in health care settings: directing, guiding, and following. The authors distinguish the 3 styles based on how much a physician makes use of 3 communication skills: listening, asking, and informing. A *directing* style would rely heavily on informing, with less asking and even less listening. The *following* style is an opposite approach whereby the physician primarily listens to the patient's questions, concerns, or ideas about a particular issue, with some asking and very little informing. Although the authors acknowledge that both the directing and following styles are important in certain clinical situations, they describe MI as most consistent with the *guiding* style, which uses a balance of listening, asking, and informing, and which they argue is most effective for health behavior change interventions.

Much of the emphasis in MI is on the listening and asking skills that Rollnick described. The dual processes of the interpersonal "MI spirit" and the focus on eliciting "change talk" have been described as the main components of the proposed theory of MI. Maintaining a patient-centered, MI-adherent approach when informing patients and caregivers about an illness or its resulting treatment options is quite a challenge for pediatricians.

The provision of information from physician to patient or caregiver may seem at odds with a patient-centered model designed to make the patient's goals and values central to the decision-making process. Rollnick et al outlined a simple and useful strategy, the Elicit-Provide-Elicit (E-P-E) sequence, to help guide physicians in providing information that maintains the autonomy and collaborative emphasis in MI. The first Elicit step is an effort by the physician to evoke ideas from the patient or caregiver about a condition or its treatment.

The Provide step in the sequence is the point at which the physician shares information or recommendations about the clinical issue at hand. Often the

information provided follows a specific request for ideas or recommendations from the patient or caregiver. An MI-adherent strategy often used in the Provide step if the patient or caregiver does not make such a request is to ask for permission before giving advice. Although patients or caregivers rarely will turn down this request, the action of asking permission reinforces the collaboration between physician and patient or caregiver.

The final Elicit step occurs when the physician offers the patient or caregiver an opportunity to comment on the information provided. This step is crucial in helping to ensure that the patient or caregiver understands the information or recommendation being shared. It also allows the patient or caregiver a chance to respond, share concerns, or modify the recommendations in a manner that fits better with the patient and caregiver lifestyle. Box 31-1 contains an example of the E-P-E sequence in the context of smoking cessation.

The E-P-E sequence, asking permission to give advice, and other MI-consistent strategies are quite different from a traditional authoritarian or prescriptive clinical approach. When a pediatrician encounters patient or caregiver ambivalence about adopting health behavior strategies, confrontation will likely lead to increased resistance. Consistent with patient-centered strategies such as MI, pediatricians will be more effective if they avoid statements such as "you must," "you should," and "you need to," which are more controlling and minimize a patient or caregiver's autonomy and responsibility for change. MI is a shared process of decision making, and the reasons for change should come from the patient's own goals and values. See Table 31-1 for a brief transcript of an MI session in the context of pediatric obesity.

MOTIVATIONAL INTERVIEWING IN PEDIATRICS—EMPIRICAL SUPPORT

Suarez and Mullins reviewed the research on MI and pediatric health behavior interventions. The authors described findings from 15 published studies (9 of which were randomized clinical trials) on the feasibility

BOX 31-1 Example of the Elicit-Provide-Elicit Sequence in the Context of Smoking Cessation

ELICIT

Physician: We've been talking a lot today about your smoking. What thoughts do you have at this point regarding your smoking?

Patient: It's not that I think it's good for me. I know about the risks. It's just that I've tried to quit before, and I never stick with it. It's so hard!

PROVIDE

Physician: It has been tough to quit on your own, and you are still concerned about the risks to your health. Could I share some information with you about quitting strategies that might help?

Patient: Sure.

Physician: Some strategies that have been very effective for other people that are trying to quit smoking are nicotine replacements, like the patch, as well as a support group.

ELICIT

Physician: What are your thoughts about those options?

Table 31-1 Transcript of Motivational Interview (MI) Session With an Adolescent Patient (Pt), Her Mother (Pt Mother), and a Dietitian (RD)

DISCUSSION	MI PRINCIPLES
RD: Tell me what you have noticed since we saw you last.	
Pt: I have to be honest. I have not done the lunch thing at all. There is no good excuse. I just haven't done it. I've done okay with the other goals, just not lunch.	Brief mention of success embedded in sustain talk
RD: You're feeling pretty good about 2 of the 3 goals you identified.	Selectively reflecting change talk
Pt: Yeah, I've been good about my stretches. That's been easier than I thought it would be. I'm also doing pretty good at not overeating at home. Sometimes I overdo it, but not as much as before.	Pt expanding on several areas of success
RD: You are persistent and you've found quite a bit of success so far.	Affirmation
Pt: I guess so, except with the whole lunch thing.	Sustain talk regarding lunch goal
RD: I appreciate your honesty. Tell me more about lunch at school. What kind of things have gotten in the way?	Open-ended question
Pt: I am just lazy. I haven't wanted to pack, and really, I just don't like to eat at school. The girls at lunch are all so skinny and complain about getting so full eating just an apple.	Sustain talk: Pt. not interested in packing lunch, struggling with other "skinny" girls
RD: It's hard seeing the other girls eating just an apple. It makes you not want to eat at school.	Reflection: Expressing empathy and rolling with resistance

Continued

Table 31-1 Transcript of Motivational Interview (MI) Session With an Adolescent Patient (Pt), Her Mother (Pt Mother), and a Dietitian (RD)—cont'd

DISCUSSION	MI PRINCIPLES
Pt: Yes, exactly. I mean, later on I kick myself for not eating lunch because I know that leads to me getting really hungry, and then I overeat. And I notice my energy is really low at practice. I just can't decide what I could pack that I like and is easy. I know my mom would pack it for me.	Increasing change talk. Listing cons of not eating lunch. Identifying barriers for success with possible solution involving mother.
RD: So on a scale from 1 to 10, how important is it for you to eat lunch at school?	Assessing importance of lunch goal
Pt: Usually a 2. Except on game days, then it's more like a 4 or 5. I have started to buy a slice of pizza on game days, but that is no good. Pizza is a bad choice.	Sustain talk and change talk
RD: What is it about game days that make it more important for you?	Open-ended question focusing on change talk
Pt: I know I need my energy to play well, and I usually can't get home before the game. So I have to eat at school. It's just that my choices could be better.	Reason for eating lunch Acknowledging possibility of better choices
RD: So, you choose not to skip lunch on game days and typically order a slice of pizza. Even though this is a step in the right direction, you are thinking about making different choices.	Reflection about changes made Affirming the effort
Pt mother: Well, you only ate one slice of pizza, not a whole box. It is great that you are eating on game days.	Mother expressing support for Tina
Pt: Actually, I use more energy on practice days because we have to run 2 miles at the start of practice and do all kinds of intense drills. I really should just take something for lunch, but I can't get myself to pack anything. And if my mom were to pack it, I can't even think about what I would want to tell her to give me.	More change talk, eliciting help from mother
Pt mother: I would be happy to pack your lunch for you, and I have asked what I could get at the grocery store for your lunches.	Supporting change talk
RD: Tina, you are interested in taking your lunch to help with your energy and your performance during soccer, you have your mom's support, and you are willing to take lunch if you can find the right thing to take.	Summary
Pt: Peanut butter sandwiches would be easy and the perfect choice but we cannot have peanut butter in the house because I always eat too much of it.	Pt developing change plan, identifies another barrier
RD: You know this is a trigger food that you overeat at home, yet eating peanut butter would be a good option for you at lunch.	Double-sided reflection ending with change talk
Pt mother: We could get the little individual containers of peanut butter, or I could keep it with me and make your sandwiches.	Family generating change plan
Pt: Yes, and we could buy the presliced apples that I can eat with my braces.	Strengthening plan
RD: So, on a scale of 1 to 10, how confident are you about your new lunch plan?	Assessing confidence of change plan
Pt: 10/10. I know this is going to work.	Change plan
RD: When do you think you can start?	Seeking commitment with start date
Pt: Mom, can we stop at the store on the way home?	Seeking help from mother
Pt mother: Absolutely.	Support
RD: Looks like you guys have a plan that you are excited about.	Reflection

From Irby M, Kaplan S, Garner-Edwards D, et al. Motivational interviewing in a family-based pediatric obesity program: a case study. *Fam Syst Health* 2010;28:236–246.

and efficacy of MI for a range of pediatric conditions and caregiver interventions: diabetes, obesity and diet, dental care, reproductive health, reducing second-hand smoke, and child behavior management interventions. The authors concluded that the emerging evidence is promising and worthy of further study.

For example, Channon et al conducted a pilot study and follow-up randomized controlled trial examining the feasibility and efficacy of MI for type 1 diabetes in adolescents. Results from both pilot and randomized controlled trial phases demonstrated the utility of MI in reducing A1C levels through a 2-year follow-up period, as well as positive outcomes on a number of psychosocial measures, such as well-being, quality of life, anxiety, and perceived impact of diabetes on the adolescents' lives. Another example was an MI intervention for caregivers designed to reduce children's (≤3 years of age) exposure to second-hand smoke. Results at 6-month follow-up showed reduced mean nicotine levels in homes of MI participants relative to controls.

CONCLUSION

The complexities of pediatric care require pediatricians to engage with patients and caregivers across a broad developmental spectrum. A major challenge in producing positive clinical outcomes is health promotion for patients and their caregivers. Early evidence supports the application of models such as SDT and motivational strategies such as MI in pediatric settings. Although more research is needed to better understand causal pathways of patient-centered strategies, the IOM and AAP have both

placed an increased focus on the use of patient-centered medicine in the promotion of health behavior changes in pediatrics.

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Chapter 32

FAMILY SUPPORT

James M. Perrin, MD; Amy Pirretti, MS

BACKGROUND

The definition of family can be complex. The following is a definition shared by the late family advocate Polly Arango to the *Bright Futures* guidelines.

> *We all come from families. Families are big, small, extended, nuclear, multi-generational, with 1 parent, 2 parents, and grandparents. We live under one roof or many. A family can be as temporary as a few weeks, as permanent as forever. We become part of a family by birth, adoption, marriage, or from a desire for mutual support. As family members, we nurture, protect, and influence each other. Families are dynamic and are cultures unto themselves, with different values and unique ways of realizing dreams. Together, our families become the source of our rich cultural heritage and spiritual diversity. Each family has strengths and qualities that flow from individual members and from the family as a unit. Our families create neighborhoods, communities, states, and nations.*
>
> DEVELOPED AND ADOPTED BY THE NEW MEXICO LEGISLATIVE YOUNG CHILDREN'S CONTINUUM AND NEW MEXICO COALITION FOR CHILDREN, JUNE 1990

The American Academy of Family Physicians defines the family as "a group of individuals with a continuing legal, genetic, or emotional relationship," indicating the varied nature of families, the complexities of assessing each family constellation, and the importance of recognizing diversity. Every family is an individual system with beliefs and attitudes of its own.

Family Trends

The number of children living with 2 married parents has decreased during the past 40 years (see Figure 32-1). In 1970, 85% of children were living with married parents, whereas 67% of children in 2010 did so. During this same period, the number of children being raised by single mothers grew from 11% to 23%. The proportion of children being raised by single fathers has fluctuated from 1% to 5% and was 3% as of 2010. The number of children living without either parent has remained constant at about 4% across the past 4 decades. Other notable family structure trends include nearly 7% of children living with a grandparent, with a parent also present in more than half of these families (data from 2010). Families have become much more diverse in the past few decades. Increasing numbers of same-sex couples have children. Children and young families have increasing racial and ethnic diversity, with larger numbers of mixed-race families. Family structure also differs significantly when stratified by race (see Figure 32-2). Almost 85% of Asian children live in families with 2 married parents, compared with 71% of whites, 61% of Hispanics, and 35% of blacks, again indicating the diversity among families and the need to inquire about household structure with all families.

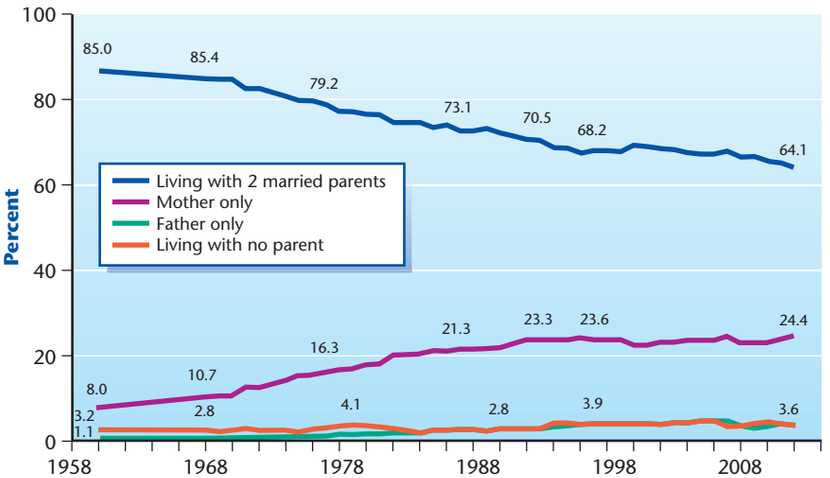
Family Culture and Behaviors

The growing racial, ethnic, cultural, and gender diversity among US children and their families reflects diverse beliefs about family roles and activities, including childrearing and discipline. Cultural variations may include rituals and activities that help to ground a developing child in her community and its stories and beliefs, including those regarding health and living healthy lives. Cultural differences can influence eating behaviors and foods offered, definitions of appropriate and inappropriate behaviors, parental efforts at control, time together and activities, and views of medications and other treatments. The family's culture is an intrinsic part of the child's social environment, and pediatricians should develop cultural awareness while learning individual family preferences.

Understanding the cultural context of the family in concert with the internal family dynamics helps the pediatrician in providing quality care and ensuring good communication within the medical home. Pediatricians can become familiar with the major cultural groups in their community and develop ways to elicit cultural beliefs that may affect a child's health or medical treatments and can implement the culturally competent tools to enhance effective understanding and communication. Guidance for providing culturally effective care can be found in Chapter 48, Providing Culturally Effective Care.

Family and Community Environments

The communities where children live influence their health and development. Communities provide



Note: Children living with 2 married parents may be living with biological, adoptive, or non-biological parents. Children living with mother only or father only may also be living with the parent's unmarried partner.

Figure 32-1 Living arrangements of children younger than 18 years, 1970–2012. *(Reproduced with permission from Child Trends Databank. Family Structure. http://www.childtrends.org/?indicators=family-structure. Updated March 2015. Accessed October 28, 2015.)*

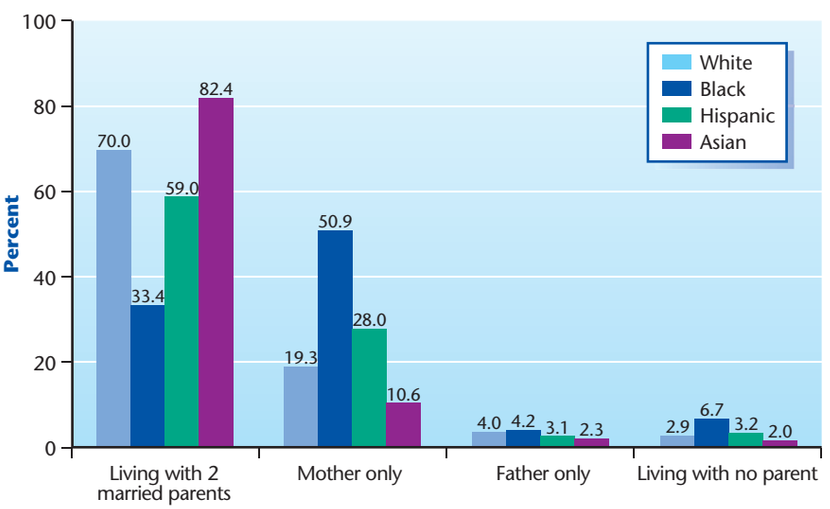


Figure 32-2 Living arrangements of children, by race and Hispanic origin, 2012. *(Reproduced with permission from Child Trends Databank. Family Structure. http://www.childtrends.org/?indicators=family-structure. Updated March 2015. Accessed October 28, 2015.)*

different levels of cohesiveness, safety, support, and beliefs, all of which have effects on the child and family. Families with children interact with a large number of community agencies and services, especially schools, which play a major role in child development and family support. Communities provide variation in opportunities for children, such as areas to play and exercise, access to nutritious foods, and exposure to potential toxins (including poor housing with mold or other antigens).

For an in-depth discussion of promoting the health of children at the community level, see Chapter 22, Promoting the Health of Young Children; Chapter 23, Promoting the Health of School-aged Children; and Chapter 24, Promoting the Health of Adolescents. Part 2, Section 4 of this textbook discusses promoting the health of specific populations of high-risk children. The discussion that follows focuses broadly on the role a child's medical home can play in enhancing families' capacity to support their children.

ENHANCING FAMILY SUPPORT IN THE PRIMARY CARE SETTING

Change, stress, and happiness that affect one family member will have reciprocal effects on all family members. The pediatrician's role in promoting families' support of their children may include surveillance of family members' health, strengths, and challenges; formal screening of caregivers for health and social problems and signs of family dysfunction; evaluation of families' social and financial resources; and anticipatory guidance to enhance the family's resilience and address the challenges parents face in nurturing their child. Medical home principles emphasize partnership with families and providing them with the tools and education to participate actively in health care.

Surveillance

To identify strength and needs of a child's family, the pediatrician might explore the following topic areas in the context of children's health supervision.

Parental Strengths and Challenges

It is important for pediatricians to identify and reinforce a parent's strengths. These may include the parent's commitment to the child's health care, relationship with the other parent, extended family connections, patience, understanding of the child's developmental needs, use of helping services, or other ways in which a parent demonstrates his or her capacities as a caregiver. By recognizing and nurturing these strengths, the pediatrician can benefit the child and build trust with the family.

It is also important to recognize the parents' health needs and socioeconomic challenges, which may affect the child's well-being. Among people aged 20 to 40 years, the main use of health care is for mental health issues and obstetric care, and large numbers of people in this age group do not seek medical care on any regular basis. Thus, key issues that parents may face in their families may go unidentified and untreated. Among the most important are parental depression, substance use, domestic violence, poverty, and separation and divorce. The pediatric encounter may play a role in identifying important parental health and social issues, especially as they pertain to the family's ability to care for the child. The following sections provide further guidance on addressing these issues when they are identified.

Family Configuration

In working with children, pediatricians should inquire about the whole family—who is in it, how they are doing, and how well their activities fit the needs of the developing child.

In general, having 2 parents, whether in heterosexual or same-sex households, involved in a child's care is associated with a number of improved outcomes. Ideally, parents share care and care decisions and recognize the value of collaborating with different adult caregivers in a child's environment. Both parents should be encouraged to share actively in child care and development; their involvement in the clinical encounter can also be encouraged.

Although many children do well in single-parent households, children in these circumstances have higher rates of school failure and developmental problems, partly reflecting much higher likelihood of poverty than in 2-parent households, as well as the additional parenting stress that accompanies parenting alone. Close connection with extended family members or other sources of support can significantly enhance the well-being of children in single-parent households.

Children whose parents divorce may have experienced much family discord and conflict and will need to adjust to the intermittent absence of 1 or both parents. Persistent conflict may also affect the child's health and behavior. Divorce may lead to new economic hardship for the child.

Parents involved in adoption or foster care face the relatively sudden inclusion of new children in a household and may know relatively little about the child's previous health or development. The children may have difficulties in new settings because of previous losses or inconsistent parenting, attachment, or bonding. Pediatricians can help parents gather more information, gain helpful skills, learn about resources, access support, and learn strategies to parent and care for a new child who may have had very different parenting experiences in the past. Identifying support and resources in the extended family may help grandparents (or others) play supportive roles. Adolescent parents may need support in developing their parenting skills, and referrals to parenting education programs that focus on young parents can help in this regard.

CAREGIVER ROLES AND INTERACTIONS. In modern families, parent roles and responsibilities vary widely, with many ways of distributing tasks, including child care, discipline, and daily activities such as supervision of homework, entertainment, eating, or sleep. Pediatricians should seek information about the role of a noncustodial parent in the household and encourage the parent's participation in various care and health areas.

A parent who is out of the home or working may feel too busy or otherwise excluded from interactions with a child's health care providers; encouraging the parent's interaction either in person or through other means of communication can help support these roles and provide broader understanding about the family.

Children With Special Health Care Needs

Children and youth with special health care needs substantially increase the time (and often physical work) of parenting. Children with diabetes need attention to diet, blood testing, and insulin treatment. Families need to understand how various life issues (illness, stress) may influence blood sugar. Children with mental health and emotional problems require behavioral management and educational guidance. Children with developmental conditions also require family support and accommodation. Asthma, arthritis, epilepsy, leukemia, and other childhood chronic health conditions create demands specific to those conditions. The child's symptoms, absences from school or child care, health care appointments, hospitalizations, and medication management may require that caregivers

interface with schools and agencies, miss work, and deplete their emotional and financial resources, compounding the stress on the child and caregivers, individually, and on the family as a unit, including siblings. Primary care pediatricians can support the family by identifying and attending to these stressors, making appropriate referrals for both the child and caregivers, and connecting them to sources of peer support and respite care.

Change and Family Stress

Families face many changes that are stressful, and their responses and adjustment to them may affect children's health. Obvious stresses include transitions—a new (parent) job, a new house, illness or death of a parent, and separation and divorce. Other transitions that the child may experience include discharge from hospital to home as a newborn or after care for a serious chronic or acute condition, entering school, or entering adolescence. Economic stresses, such as a parent's job loss or chronic unemployment, may have a powerful effect on the family's capacity to attend, physically and emotionally, to the child's needs. Indeed, family stressors, large and small, are very common. Chronic, toxic stress may have immediate and long-term negative health consequences for the child. (See Chapter 68, Children Exposed to Adverse Childhood Experiences.)

Pediatricians can help by querying about recent changes in the household or new stresses that the family may be experiencing. A brief mental health update can be adapted for this purpose.

When the pediatrician finds stresses that may affect family well-being, she can use common factors techniques (see Chapter 46, Effective Communication Strategies) to strengthen the therapeutic alliance with the family and develop a family-centered plan of action. The plan may include general steps to improve the family's health and resilience (eg, physical activity, sleep, help from friends or extended family, connection with spiritual resources) and specific referrals for mental health care, marital or financial counseling, social services, or peer support. The pediatrician's demonstrated empathy, hopefulness, and commitment will likely have their own therapeutic value.

Screening

Parents may hesitate to bring up their stresses or personal health problems during pediatric visits, despite their importance in affecting child care and health. Brief screening tools exist to help pediatricians identify these concerns in a family.

Anticipatory Guidance

To nurture a family's capacity to support its children, the pediatrician will need a relationship of trust with the family. The 2008 American Academy of Pediatrics Task Force on Mental Health report provides guidance on making a primary care practice a friendly environment for the discussion of family issues that may affect the child's health and well-being. Understanding and supporting the family in a family-centered medical home will, in turn, enhance the child's health and development.

Any clinical encounter offers opportunities for reinforcing the family's strengths and enhancing the family's capacity to support the child with challenges that lie ahead. This guidance may take many forms, depending on the family's readiness to accept help and the needs of the child. For example, the pediatrician may have an opportunity to advise new parents on the importance of their communication with the pediatrician, particularly emphasizing that child care providers should not use TV screens as babysitters; to encourage the parent of an adolescent to stay involved in the child's daily activities; to recommend a counselor for parents undergoing separation or divorce; or to involve extended family in supporting a parent facing military deployment.

Families needing additional support can be referred to helping agencies or peer support programs. Evidence-based programs such as the Nurse Family Partnership and early literacy promotion can assist caregivers in strengthening bonds with their children. For children and youth with special health care needs, legislative efforts have led to development of Family-to-Family Health Information Centers (F2F HICs) in each state. Staffed by parents of children with special health needs, the F2F HICs assist families and pediatricians in locating community resources.

SUMMARY AND RECOMMENDATIONS

In many ways, pediatricians are physicians for the whole family. Thus, much clinical interaction relates to learning about family strengths and capabilities, understanding circumstances in which family health issues and stressors may affect a child's health, and determining with the family best strategies to identify and address a child's health needs in the family context. Pediatricians should know about community resources and refer appropriately.

In developing therapeutic relationships with children and families, pediatricians should take into consideration the diversity of families and family structures, the involvement of various adults in the relationship, variations in household and community culture and language, parental health and socioeconomic status, and the effect of the child's health condition on the family. Providing effective preventive care and anticipatory guidance builds on an understanding of the family and its characteristics, strengths, and challenges.

TOOLS FOR PRACTICE

Community Advocacy and Coordination

- *Adolescent and School Health* (Web page), Centers for Disease Control and Prevention (www.cdc.gov/healthyyouth/schoolhealth/index.htm)
- *Building the Legacy: IDEA 2004* (Web page), US Department of Education (idea.ed.gov)
- *Connected Kids Clinical Guide* (handout), American Academy of Pediatrics (www2.aap.org/connectedkids/ClinicalGuide.pdf)
- *Culturally Effective Care Toolkit* (toolkit), American Academy of Pediatrics (www.aap.org/en-us/professional-resources/practice-support/Patient-Management/Pages/Culturally-Effective-Care-Toolkit.aspx)

- *Health, Mental Health, and Safety Guidelines for Schools* (Web site), American Academy of Pediatrics (www.nationalguidelines.org)
- *National Association of County and City Health Officials Toolbox* (handouts), National Association of County and City Health Officials (www.naccho.org/toolbox)
- *The National School Lunch Program* (Web page), US Department of Agriculture (www.fns.usda.gov/nslp/national-school-lunch-program-nslp)
- *State School and Health Resources* (Web page), American Academy of Pediatrics (www2.aap.org/sections/schoolhealth/contactmap/section_contacts.cfm.htm)
- *USDA Food and Nutrition Services* (Web site), US Department of Agriculture (www.fns.usda.gov)

Engaging Patient and Family

- *Child Care Aware Resources* (Web page), Child Care Aware (childcareaware.org/parents-and-guardians/resources)
- *Community Health Online Resource Center* (handouts), Centers for Disease Control and Prevention (nccd.cdc.gov/DCH_CHORC)
- *Frequently Asked Questions About Section 504 and the Education of Children With Disabilities* (fact sheet), US Department of Education (www.ed.gov/about/offices/list/ocr/504faq.html)
- *Head Start: About Us* (Web page), Office of Head Start (eclkc.ohs.acf.hhs.gov/hslc/hs/about)
- *National Center for Children in Poverty Data Tools* (Web page), National Center for Children in Poverty (nccp.org/tools)
- *Office of Child Support Enforcement* (Web site), Office of Child Support Enforcement (www.acf.hhs.gov/programs/css)
- *Rental Assistance* (Web page), US Department of Housing and Urban Development (portal.hud.gov/hudportal/HUD?src=/topics/rental_assistance)
- *Social Security* (Web site), Social Security Administration (www.ssa.gov)
- *Supplemental Nutrition Assistance Program* (Web site), US Department of Agriculture (www.fns.usda.gov/snap)

AAP POLICY

American Academy of Pediatrics Committee on Psychosocial Aspects of Child and Family Health. Coparent or second-parent adoption by same-sex parents. *Pediatrics*. 2002;109(2):339–340. Reaffirmed May 2009 (pediatrics.aappublications.org/content/109/2/339)

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Chapter 33

HEALTHY CHILD DEVELOPMENT

Marian Earls, MD

Primary care physicians (PCPs) who care for children and youth have the opportunity at every encounter with the family to promote healthy development—motor, language, cognitive, and social-emotional. Recent understanding of brain development highlights the importance of social-emotional development. Pediatricians know from brain research that experience affects brain development, both prenatally and postnatally. The implications for prevention and intervention are profound because growth, development, and behavior are inextricably linked. This chapter describes the PCP's role in promoting healthy child development, identifying developmental problems, and involving other professionals in the child's care when needed.

BACKGROUND

Approximately 15% of children have developmental or behavioral disabilities, including speech and language delays, attention-deficit/hyperactivity disorder, intellectual disability, learning disabilities, cerebral palsy, autism, hearing loss, blindness, and emotional problems. Even at preschool age, 13% of children have mental health problems. In 2005 the Centers for Disease Control and Prevention reported that 5% of 4- to 17-year-olds in the United States (2.7 million children) were described by their parents as having severe emotional or behavioral difficulties in the National Health Interview Survey. These rates increase with the co-occurrence of risk factors such as poverty, maternal depression, substance abuse, domestic violence, and foster care placement. According to the National Center for Children in Poverty, in 2015 approximately 44% of children in the United States lived in low-income families. This number has been increasing since 2000, after a decade of decline. These children have an increased risk for language, learning, and behavioral problems. An infant living with a depressed mother can show disordered attachment as early as 2 months of age and is at risk for failure to thrive, impaired social interaction, and delays in language and cognitive development. For the older child or adolescent, there is increased likelihood of depression, anxiety, behavior problems, or conduct disorder. Many premature infants, especially those of extremely low birth weight (<1000 g), are at risk for

visual and hearing impairment, language delays and learning problems, and problems with motor development. In addition, for an infant who has had a prolonged neonatal intensive care unit course, bonding can be a challenge, particularly if ongoing medical or feeding issues exist.

Despite the medical community's knowledge of prevalence and risk, detection of developmental and behavioral problems before school age is very poor (<50%). This circumstance limits the possibility of early intervention. By contrast, 70% to 80% of children with developmental disabilities are correctly identified when standardized screening tests are used.

Screening rates for development and behavior, maternal depression, and family risk or protective factors have been poor in primary care practice. The American Academy of Pediatrics (AAP) Survey of Fellows No. 53 in 2002 revealed that 71% of fellows used only clinical observation without a screening instrument to identify children with a developmental delay. Only 23% reported using a standardized tool. Reasons given for not screening include that screening takes too long, tools are difficult to administer, children may not cooperate (an understatement with a screaming 2-year-old), and reimbursement is limited. Perceived barriers are time, cost, and staff required.

Despite these perceived barriers, during the past several years, national efforts such as the Commonwealth Fund's ABCD (Assuring Better Child Health and Development) Project have increased developmental and behavioral screening, referral, and coordination of care in practices across many states. Since 2000 there have been many successful models of screening in primary care practices, including developmental and behavioral screening, maternal depression screening, and psychosocial screening. In these projects, strategies have been implemented to integrate screening into office flow, to improve reimbursement, and to assist practices in identifying and collaborating with community resources, including mental health resources. The ABCD Project, funded by the Commonwealth Fund and administered by the National Academy for State Health Policy, has involved 28 states and their AAP chapters. The AAP, in addition to its screening policy statements, promotes screening through outreach, continuing education, and quality improvement activities. According to the National Survey of Children's Health 2011, the use of standardized, parent-completed developmental screening in primary care has been increasing (parents reported completing a standardized developmental screening tool in the past 12 months at a health care visit for a child between 10 months to 5 years of age 30.8% of the time in 2011, up from 19.5% of the time in 2007). Likewise, in 2009 the Survey of Fellows No. 74 revealed that 47.7% of pediatricians reported using a standardized tool (which had doubled since 2002). Those using only clinical observation decreased to 60.5%.

Early identification allows for referral and early intervention, even for children with significant developmental diagnoses that cannot be cured or completely remediated. Early intervention improves function for the child and family and allows for linking families with community supports. Early intervention can also save up to $100,000 per student in special education costs over the course of the child's education. However, although 15% have a developmental disability in childhood, only 2% to 3% receive public early intervention services by 3 years of age.

In the care of the child or adolescent, then, it is necessary to consider the whole child, including social and emotional development, in the context of family, school, and community. Routinely assessing risk allows for early implementation of preventive strategies.

OFFICE-BASED HEALTH PROMOTION

The primary medical home provides the perfect setting for screening and surveillance, improving prevention, and early identification. The promotion of healthy development using a strengths-based approach is a central emphasis of the Bright Futures health supervision guidelines. Bright Futures health promotion themes include family support, child development, and mental health. The PCP's longitudinal relationship with the child and family is a key component of the "primary care advantage" described in the AAP statement regarding mental health competencies in primary care. Discussing assets and promoting connections for support are part of early and ongoing conversations with families, along with open discussion regarding risk factors.

Promotion of healthy development begins with the prenatal visit. At that visit, the longitudinal relationship begins, and the discussion of family assets and supports as well as stressors occurs. Early identification of risk factors, such as maternal depression, allows for early strategies to support the mother and family so that the infant is born into a nurturing environment. Reach Out and Read is an excellent example of health promotion. By reading to the infant, toddler, or preschooler, in a single activity the parent encourages healthy social-emotional (cuddling to read), language (imitating and pointing), and fine motor (reaching and turning pages) development. Encouraging the sharing of age-appropriate books together from an early age has benefits for the relationship, developing language skills, and success with early reading skills.

Asking the child or adolescent about his or her best and favorite subjects at school is as important as discussing where he or she has difficulty. PCPs partner with parents in encouraging the child about school (participation in class and completing homework) as well as in advocating for assessment and intervention for students who may have learning or attention difficulties. Showing interest in and encouraging prosocial activities for children and adolescents are powerful tools for the PCP; such activities help young people explore their talents and promote belonging. Examples include clubs, sports teams, dance, band, and choir. Particularly for adolescents, encouraging volunteerism and community activities is positive for building self-esteem and reducing risk behaviors. For adolescents, a useful model to promote such protective factors is the Circle of Courage mnemonic GIMB: generosity, independence, mastery, and belonging.

As part of routine care, the PCP should engage the family in discussion regarding parental well-being, family supports, and information about child care or school. To this end, the PCP would routinely perform developmental and behavioral surveillance and standardized

screening. PCPs who provide care for children and adolescents have long recognized the importance of developmental and behavioral screening and surveillance in helping families optimize their children's acquisition of skills, understand behavior, and facilitate learning. For children who may have developmental differences or delays, regular periodic screening provides the opportunity for early identification and referral for intervention. Screening not only has the benefit of early identification but also is an excellent promotional strategy in that a screen provides a discussion template for anticipatory guidance and asset building.

A strengths-based approach is of central importance. It is the PCP's role to elicit both strengths and concerns. From an early age the child should participate in reporting his or her strengths and concerns. This builds the relationship with the child and helps prepare for communication between the PCP and adolescent. The Search Institute documented the protective effect of assets when a child or adolescent is exposed to risk. The asset categories include external assets (support, empowerment, boundaries, and expectations, and constructive use of time) and internal assets (commitment to learning, positive values, social competencies, and positive identity).

When social-emotional, behavioral, or mental health concerns are voiced, the AAP Task Force on Mental Health recommends a "common factors" approach, applying motivational interviewing and other communication skills to engage the family in developing a plan for addressing the issue together and considering follow-up and referral if necessary. (See Chapter 46, Effective Communication Strategies.)

IMPLICATIONS FOR PRACTICE

The PCP does not need to become an expert at diagnosing and managing developmental and behavioral disorders, nor a mental health professional. However, the PCP has the "primary care advantage" noted earlier, with the opportunity for surveillance and screening, discussion of findings with the family (and child or adolescent), referral for further assessment and intervention, and monitoring of the child and family's progress over time. The PCP has multiple roles: a partner with the family in finding information and community resources, a sounding board, a facilitator in negotiating the system, and comanager of care with other specialists.

Promotion and early identification involve both surveillance and screening. Surveillance is the routine elicitation of family and patient concerns about development, behavior, or learning; it is generally accomplished by conversation and observation. It is part of the longitudinal relationship and occurs at every visit (Table 33-1). Formal screens are used at important intervals to understand and document development and to detect problems that are not observable through surveillance alone.

Primary developmental and behavioral screens and psychosocial screens can be interwoven into the schedule of well-child visits and into the growing relationship with the family. Screening may involve the family social environment and caregivers as well as the child. Screens are included in the routine health supervision schedule in anticipation of critical turning points. However, these screens are meant to be flexible to respond to individual family concerns.

Family psychosocial surveillance begins with the first visit with the family and is really part of the history-taking process. It can then take place with any updating of history at later visits. Specific psychosocial screens can be interwoven into registration material when a family first comes to the practice, at visits when developmental screening questionnaires are not being used, and into the conversations between the physician and parents at any visit. Screening should be routine for all families, not targeted because of assumptions about risk. Psychosocial screening includes asking about family relationships, maternal depression, domestic violence, substance abuse, and finances. Other important

Table 33-1 Development: Possible Areas of Concern by Domain and Age

	GROSS-MOTOR	FINE-MOTOR	LANGUAGE AND COMMUNICATION	PROBLEM SOLVING	SOCIAL-EMOTIONAL
Infancy (0–1 yr)	Milestones: crawling, sitting, walking	Early: visual tracking, reaching Later: pointing, pincer grasp	Early: responsive vocalizing Later: gestures, first words, responses to name	Transferring object hand to hand, poking with index finger	Social smile, state regulation, temperament, play
Early childhood (1–5 yr)	Mastery of walking, coordination, ability to jump, running	Stacking, pencil grasp; fine motor control	Joint attention, pointing, expansion of vocabulary, forming sentences, ability to tell a story in sequence	Imaginary play; functional use of objects, cooperative play	Tantrums, problems in child care, ability to share
School age (6–10 yr) and adolescent (11–20 yr)	Coordination, control; difficulty with physical education class	Handwriting, completion of written work, note taking	Reading, phonics, written language; language organization; getting thoughts on paper	Homework organization; attention, concentration	Peer relationships, family relationships, participation, motivation, affect

questions regarding stable housing, financial resources, and insurance coverage are also pertinent.

Routine standardized screening, appropriate to the developmental age of the child, is a recommended part of the well-child schedule from infancy through adolescence. Informal checklists, in use by many primary care physicians, have no validated criteria for referral and result in missed referral opportunities. If a problem is already observable, then a screen is unnecessary and the pediatrician can proceed directly to discussion and referral, optimizing time for intervention.

Discussion of Findings

Developmental and behavioral screening allows early identification of potential problems or delays. Of equal importance, screening also reviews appropriate expectations at a given developmental age, facilitating understanding regarding the child's behavior and potentially facilitating appropriate use of discipline by parents. A conversation about the screening identifies the child's strengths and weaknesses, gives a template for anticipatory guidance, and elicits and respects parental concerns. In this way, parental self-efficacy and confidence are promoted. The physician should review and discuss the screen—whether negative or positive—with the parents (and child or adolescent) at the time of the visit. The screen provides a template for anticipatory guidance, facilitates patient flow (by reducing "doorknob concerns"—those expressed as the physician leaves the examination room), and improves patient and physician satisfaction.

If surveillance or screening suggests that a developmental problem may be present, the PCP's role is to explain the findings and seek agreement with the child or adolescent and family on next steps, which may include further assessment, intervention, or both. Families are in varied stages of readiness for this conversation. Common factors for communication skills, discussed in Chapter 46, Effective Communication Strategies, are applicable to engage the family and address barriers such as denial, resistance, and conflict that may impede follow-through with referral.

Referral

If a screen has an at-risk score, then the PCP initiates a more detailed assessment. For the young child, this assessment is generally performed outside the practice (eg, by a developmental and behavioral pediatrician, geneticist, neurologist, infant-toddler specialist, psychologist, speech and language pathologist, or physical therapist). When screenings reveal risk, the office is the source for initial discussion and referral to community resources. This role assumes previous networking by the practice with community partners and a working knowledge of and connection to community providers such as counselors, agencies, early intervention programs, child care, Head Start, and schools. For children aged 0 to 5 years with at-risk scores, referral to early intervention services occurs. Early intervention for 0- to 3-year-olds is covered under Part C of the federal Individuals With Disabilities Education Act (IDEA); early intervention for 3- to 5-year-olds is covered by Part B of IDEA and is provided by the school system. A school-aged child or adolescent may need assessment through the school's exceptional children program or through other specialists, as with the young child. For a parent whose child has a medical condition or developmental problem, a connection to a family support network can provide parent-to-parent support. Early empowerment for parenting has implications for long-term outcomes, including readiness to learn, school success, and social success. In a family-centered medical home, financial issues need to be considered for each family for a plan of care to be realistic and practical (eg, for cost of medication or transportation to a referral).

Office Process

Integrating surveillance and screening into the office process and flow is crucial for successful implementation of screening programs. Once integrated, the process is routine and occurs reliably. Prompts at appropriate ages can be made part of an electronic health record. Parent-completed (and child- or adolescent-completed) screens can be performed in the examination room while waiting for the physician or in the waiting room. With the advent of electronic health records and their associated secure patient portals, parents and patients may be able to complete the screens from home before the visit. For those who do not have access to the Internet at home, a kiosk can be made available at the practice for screen completion just before the visit. Use of a portal also eliminates the need to scan a paper screen into the record.

Steps include the following:

1. Assess protocols for developmental and behavioral screening already in use in the practice.
2. Map the workflow. This process needs to include the physician, nursing staff, and office manager and should be tailored to the practice. For example, the nurse can give the screening tool to the parent at intake to be completed in the examination room so as to be ready for the physician to review and score after coming into the room.
3. Select tool or tools. See the following section for further discussion of this step.
4. Identify system supports for parent education, referral, and community services.
    1. Meet with key partners. Inviting community partners to a lunch meeting at the practice to share screening plans and align goals is a good idea.
    2. Establish a process for referral and communication.
5. Orient all staff members to new procedures.

Billing issues are an important aspect of screening. For general developmental and behavioral screening tools (eg, Ages and Stages Questionnaire [ASQ], Parents' Evaluation of Developmental Status [PEDS], Modified Checklist for Autism in Toddlers, Revised With Follow-Up [MCHAT-R/F]), the American Medical Association Current Procedural Terminology code is 96110. The code 96127 is for behavioral and emotional screening tools (eg, Vanderbilt, Pediatric Symptom Checklist [PSC], Patient Health Questionnaire-9 [PHQ-9] Modified for Adolescents). These codes can be billed with a well-visit code or an evaluation and management code and have 0.36 relative value units.

DEVELOPMENTAL AND BEHAVIORAL SCREENING TOOLS

Parents generally give accurate and high-quality information, and they are good reporters of what their child can do. Parents' concerns are accurate indicators of true problems, particularly for speech and language, fine-motor, hearing, and general function. When asked how old their child acts compared with other children, parent estimations correlate well with developmental quotients for cognitive, motor, self-help, and academic skills. Recall (eg, milestones) is unreliable, however. For tools completed by a parent, an inclusive reading level must also be considered, although the best tools have been developed with an eye to readability. If parental reading skills are a concern, then parents can be asked if they would like to complete the screen independently or have someone go through it with them. Language availability is an important consideration in some practices. Several advantages exist to using a parent questionnaire, not the least of which is that it is a family-centered process, recognizing the parent as the expert on the child. The parent is engaged as a partner in the care of the child. A parent-completed tool can address concerns about time and efficiency. A parent tool does not require administration by staff and can be completed while the parent is in the waiting room or examination room so that it does not impinge on visit time or office flow. In the case of young children, it also removes the problem of trying to elicit skills from a toddler or preschooler by a virtual stranger and in a setting that is not the child's natural environment.

Developmental and behavioral screening tools are of different types and include direct elicitation, interview, and questionnaires completed by parents and the child or adolescent. Effective screens have sensitivity and specificity of at least 70% to 80%. The tools referred to next do not reflect an exhaustive list but are conducive to use, and commonly used, in primary care practice.

Surveillance

- Routine elicitation of family and patient concerns about development, behavior, or learning
- Generally accomplished by conversation and observation

Primary Screening

- Formal screening done with the *total* population to identify those who are at risk
- Examples include ASQ, PEDS, Survey of Well-Being of Young Children (SWYC), PSC, Strengths and Difficulties Questionnaire (SDQ), Bright Futures Adolescent Supplemental Questionnaires, Edinburgh, and PHQ-2
- These are tools with validation and cutoff scores, except for the adolescent screens that ask about specific risks and strengths but do not have a numeric score

Secondary Screening

- More specific screening done when risk is identified on a primary screen
- Examples include the ASQ Social-Emotional (ASQ-SE), Screen for Child Anxiety Related Disorders (SCARED), Children's Depression Inventory (CDI), Center for Epidemiological Studies Depression Scale for Children (CES-DC), PHQ-9 Modified for Adolescents, Vanderbilt, Conners
- Note that a specific screen may be used as a primary screen if there is known risk in a given population Examples include MCHAT-R/F, CRAFFT (tool to screen adolescents for high risk of substance abuse)

Evaluation and Assessment

- Goes beyond screening to ascertain diagnosis and develop recommendations for intervention or treatment
- This is generally not done by the primary care medical home, unless colocated or integrated professionals are in the practice. For example, evaluation is done by Part C (Early Intervention Services for children 0 to 3 years of age), in the schools, by a developmental and behavioral pediatrician, psychologist, psychiatrist, geneticist, or other physician or specialist

Primary Screens

Primary screens cover several areas of development, including gross and fine-motor, language, learning and problem-solving, social-emotional, and behavioral development.

For young children, commonly used (practical in a busy primary care practice) screens included in this group are the ASQ-3, PEDS, PEDS Developmental Milestones (PEDS DM), SWYC, and the Infant Developmental Inventory (IDI). For children born prematurely, screens should be used according to adjusted age until 2 years of age. The MCHAT-R/F screens for risk for autism spectrum disorders and is recommended routinely by the AAP at the 18- and 24-month visits. The follow-up questions for the MCHAT-R/F are used to clarify parental responses on the MCHAT tool and increase the tool's positive predictive value. For a complete description of tools with information on forms, content, sensitivity, and specificity, and for ordering, refer to the AAP Section on Developmental and Behavioral Pediatrics Web page on screening and assessment (www2.aap.org/sections/dbpeds/screening.asp). Excluded tests, as a result of poor validation or sensitivity and specificity, are the Prescreening Developmental Questionnaire, the Denver Developmental Screening Test II, Developmental Indicators for the Assessment of Learning III, and Gesell Developmental Observation Test.

For older children and adolescents, the domains of development are reflected in learning skills (reading, written language, organization, attention, academics) and social skills. Primary screening tools include the PSC, SDQ, and Bright Futures Adolescent Supplemental Questionnaires for ages 11 through 20 years. These have tools for the child and adolescent as well as for the parent to complete. For adolescents there is also the HEADSSS (Home and Environment, Education and Employment, Activities, Drugs, Sexuality, Suicide/Depression, and Safety) interview that assesses strengths and risks.

A comparison of primary screening tools by time, staff, reading level, and language availability is shown in Table 33-2.

Table 33-2 Primary Developmental and Behavioral Screening Tools

	ASQ-3	PEDS	PEDS DM & PEDS	IDI	BRIGANCE	SWYC	MCHAT R/F	PSC	SDQ	BRIGHT FUTURES
TYPE	Parent Questionnaire	Parent Questionnaire	Parent Questionnaire	Parent Questionnaire	Direct Elicitation	Parent Questionnaire	Parent Questionnaire	Parent/ Youth Questionnaire	Parent/Youth Questionnaire	Parent/ Youth Questionnaire
AGES	1 mo–5 yrs	0–8 yrs	0–7 yrs, 11 mos	3–18 mos	0–35 mos 3-5 yrs	2 mos–-5 yrs	16–30 mos	4–18 yrs	3–16 yrs	11–21 yrs
STAFF REQUIRED (to admin and or score)	Paraprofessional (to score)	Paraprofessional (to score)	Paraprofessional (to score)	Paraprofessional (to score)	Professional (to admin & score)	Paraprofessional (to score)	Paraprofessional (to score), and ask follow-up questions (if needed)	Paraprofessional (to score)	Paraprofessional (to score)	Paraprofessional (to score)
COST	Purchase kit	Purchase starter kit	Purchase starter kit and family books for exam rooms	Purchase kit	Each age range: purchase manual and data sheets	Public domain freely downloadable	Public domain freely downloadable	Public domain freely downloadable	Public domain freely downloadable	Purchase BF Toolkit
REFILLS/ COPIES	OK to copy after purchase of kit(s)	Purchase refills	Purchase refills for scoring sheets	Purchase refills	Purchase refills	Copy	Copy	Copy	Copy	OK to copy
TIME	3 min to score	5 min to score	5–10 min to score	10 min to score	10–15 min to admin	5–10 min to score	3–5 min to score	3–5 min to score	10 min to score on-line scoring available	Review by PCC
LANGUAGES	English Spanish	English Spanish Vietnamese	English Spanish	English Spanish	English Spanish	English, Spanish, Burmese, Nepali, Portuguese	English, Spanish plus 27 languages	English Spanish Chinese	71 languages	English
READING LEVEL	4th–6th grade	5th grade	3rd–4th grade	Not specified	NA		Not specified	Not specified	Not specified	Not specified

Secondary Screens

For children who screen at risk for social-emotional problems, on a general screen or because of known risk factors, effective social-emotional screens are available to help the PCP in the medical home make decisions about referrals and types of interventions. A secondary screen can be performed at a follow-up visit with the PCP, by an integrated mental health provider in the practice, or by a care manager. Alternately, the primary care practice may opt not to do secondary screening and to refer for further assessment when the primary screen indicates an at-risk area. As an example, the ASQ-SE is an appropriate tool to be used if an ASQ or a parent or provider concern indicates risk. Practical tools for the very young child include the ASQ-SE and the Early Childhood Screening Assessment (ECSA). The SWYC (for 0- to 5-year-olds) actually incorporates the Baby Pediatric Symptom Checklist and the Preschool Pediatric Symptom Checklist. Therefore, for practices using the SWYC as a general tool, a social-emotional screen is also included. For older children, tools include the CDI, CES-DC, SCARED, PHQ-9 Modified for Adolescents, and CRAFFT (substance abuse). Bright Futures recommends screening for depression at every well visit from age 11 through 21 years. The US Preventive Services Task Force recommends routine screening for depression in adolescents. Routine screening for depression from age 12 years and up is a Meaningful Use measure (National Quality Forum #418).

Family Psychosocial Screening

For family psychosocial screening, a variety of tools are available, ranging from brief to general, that incorporate a range of topics. Most of these tools screen for maternal depression, domestic violence, and substance abuse. These can identify both parental ACEs and risk for ACEs and toxic stress for the child. These psychosocial factors have significant impact on healthy development. Examples of such screens include the following:

- Kemper-Kelleher: includes questions about parent's childhood experiences (substance use and abuse, discipline, abuse and neglect, foster care), depression, substance use, support
- SWYC: includes questions about smoking, substance use, food availability, depression, domestic violence
- SEEK (A Safe Environment for Every Kid): includes questions about smoking, guns, food availability, depression, substance use, discipline, domestic violence
- Parents' Assessment of Protective Factors, from Strengthening Families, Center for the Study of Social Policy
- Edinburgh: postpartum depression

Bright Futures highlights the importance of addressing these risk areas and identifying family protective factors to promote the healthy development of the child. (See Chapter 34, Mental Health.)

For an overview of how these various tools may be integrated into the well-child schedule, see Table 33-3, which incorporates the screenings based on current recommendations. See Chapter 32, Family Support, for more information about use of these tools.

SUMMARY

Promotion of healthy development begins as early as the prenatal visit and continues through the longitudinal relationship of the PCP with the child and family. Routine discussion of assets and risks is an essential health promotion and preventive strategy. Opportunities for promoting healthy development and identifying developmental problems include prenatal visits, surveillance, psychosocial screening of both the child and family, developmental and behavioral screening of the child, and secondary social-emotional and mental health screening of children and adolescents at

Table 33-3 Healthy Child and Adolescent Development: Promotion and Screening for Risk

VISIT	PRIMARY SCREEN/ SURVEILLANCE	CONCERN	FOLLOW-UP SCREEN	REFERRAL CONSULTATION	INTERVENTION
AGE 0–5 YR					
1, 2, 4 mo	Edinburgh/PHQ-2	Postpartum depression	ASQ-SE	MHP	E-B therapy EI Part C
9, 18, 24, or 30 mo	ASQ/PEDS/SWYC, etc.	Motor, language Social-emotional	ASQ-SE	MHP	EI Part C E-B therapy
36, 48, 60 mo		Motor, language Social-emotional	ASQ-SE	MHP	EI Part B E-B therapy
Any	At-risk psychosocial situation	Maternal depression, DV, SA	ASQ-SE	MHP	E-B therapy
Any	Parent concern	Motor, language Social-emotional	ASQ-SE	MHP	EI E-B therapy, EI
18 and 24 mo	MCHAT-R/F	ASD			EI Part C

Continued

Table 33-3 Healthy Child and Adolescent Development: Promotion and Screening for Risk—cont'd

VISIT	PRIMARY SCREEN/ SURVEILLANCE	CONCERN	FOLLOW-UP SCREEN	REFERRAL CONSULTATION	INTERVENTION
AGE 6–10 YR					
Every well visit	PSC/SDQ	Depressive symptoms	CDI, CES-DC	MHP	CBT
		Anxiety	SCARED	MHP	CBT
		Learning, school behavior problems	Vanderbilt and school records	School evaluation	IEP for OHI/LD
AGE 11–20 YR					
Every well visit	Bright Futures Supplemental	Function Depressive symptoms	SDQPHQ-9 Modified for Adolescents	MHP	CBT
	HEADSSS	Anxiety	SCARED	MHP	CBT
		Learning, school behavior problems	Vanderbilt and school records	School evaluation	IEP for OHI/LD
	CRAFFT	Substance use, abuse		MHP	E-B therapy

CBT, Cognitive behavioral therapy; *E-B*, evidence-based; *EI*, early intervention; *IEP*, Individualized Education Plan; *LD*, learning disabilty; *MHP*, mental health professional (integrated in practice or in community); *OHI*, other health impaired.

risk. The use of routine standardized screening tools at recommended intervals enhances surveillance and the ability to identify risk early. The roles of the medical home include the following:

- Develop a reliable system for integration of surveillance, screening, referral, follow-up, and linkage to resources into the office workflow.
- Develop relationships with specialists and community agencies to include standardized referral and feedback processes.
- Follow criteria for referral after a positive screen. There is *no rationale* for a "wait and see" approach because it delays early intervention.

When developmental problems are identified, the PCP uses the "primary care advantage" to engage the child or adolescent and family in developing a plan for further assessment and care. The PCP refers, if necessary, and communicates and collaborates with specialists, schools, and other providers in the monitoring and ongoing care of the child or adolescent.

AAP POLICY

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Chapter 34

MENTAL HEALTH

Jack T. Swanson, MD; Jane Meschan Foy, MD

BACKGROUND: THE PEDIATRICIAN'S ROLE IN PROMOTING CHILDREN'S MENTAL HEALTH

Children's mental health—including all its psychosocial and emotional aspects—is an intrinsic part of their overall health and well-being. The pediatrician has an important role to play in influencing the intentional pursuit of optimal mental health as part of each child's development. Good mental health has been described as "the reasonable, regular experience and effective practice of

- Confidence and courage
- Adaptability
- Cheerfulness
- Attention/concentration
- Harmony
- Hardiness
- Social connectedness"

The foundation of mental health begins before birth, with the parents' and caregivers' own well-being and with preparations they make for the physical and emotional care of the child. Caregivers continue to build on this foundation after the child's birth by providing their attention and love in a safe and nurturing environment. This environment expands from the child's home to include the child care setting, school, and community. Box 34-1 provides examples of the skills needed by caregivers in all settings to nurture social and emotional competence in a young child.

While fostering mental health is, in practice, intertwined with fostering healthy development generally, Chapter 33, Healthy Child Development, provides context for the present chapter.

Each stage of childhood provides pediatricians with unique opportunities to promote children's mental health during regular contacts with the child and his or her caregivers. These unique opportunities, described by the American Academy of Pediatrics (AAP) Task Force on Mental Health (TFOMH) as the "primary care advantage," include:

- A longitudinal, trusting, and empowering therapeutic relationship with children and family members
- A family-centered medical home
- Regular contacts in which to promote healthy lifestyles; foster the skills caregivers need to promote children's social and emotional competence; reinforce child and family strengths; recognize adverse childhood experiences and stressors (see Chapter 68, Children Exposed to Adverse Childhood Experiences, for a discussion of the importance of this); offer anticipatory guidance, including strategies for self-soothing and stress management; and provide timely intervention for common problems
- Understanding of common social, emotional, and educational problems in the context of a child's development and environment
- Knowledge of community resources to assist children and families in building resilience and addressing the mental health challenges they encounter.

Mental health problems occur often during childhood and adolescence. In the United States, between 9.5% and 14.2% of children from birth to 5 years experience social-emotional problems that cause suffering to the child and family and interfere with functioning. More than 20% of children ages 9 to 17 have a diagnosable mental health disorder, and another 16%

BOX 34-1 Examples of Caregiver Skills to Promote Social and Emotional Competence

- Engage infants in frequent face-to-face social interactions each day (verbal and nonverbal behaviors).
- Quickly respond to infants' and toddlers' cries or other signs of distress by providing physical comfort and needed care.
- Support children's development of friendships and provide opportunities for children to play with and learn from each other.
- Help children practice social skills and build friendships by helping them enter into, sustain, and enhance play.
- Help children resolve conflicts by helping them identify feelings, describe problems, and try alternative solutions.
- Help children talk about their own and others' emotions; provide opportunities for them to explore a wide range of feelings and the different ways to express them.
- Actively teach children social communication and emotional regulation.
- Help children manage their behavior by guiding and supporting them to: (1) persist when frustrated; (2) play cooperatively with other children; (3) use language to communicate needs; (4) learn turn-taking; (5) gain control of physical impulses; (6) express negative emotions in ways that do not harm others or themselves; (7) use problem-solving techniques; and (8) learn about themselves and others.

From National Association for the Education of Young Children (NAEYC). NAEYC Early Childhood Program Standards and Accreditation Criteria & Guidance for Assessment. Updated October 1, 2015. www.naeyc.org/academy/torch-resource/naeyc-early-childhood-program-standards-and-accreditation-criteria-guidance-assessmen. Copyright © 2015 National Association for the Education of Young Children.

or more of children have impaired mental health functioning without a diagnosable mental health disorder. Furthermore, half of adults with mental health disorders experienced the onset of symptoms by age 14. Parents' misperceptions about their children's behavior may also be an issue: 10% to 13% of children have parents who think their child has a behavioral problem when the child is, in fact, functioning normally for his or her age. Mental health problems are more common among children with chronic medical or developmental conditions and among those who have experienced abuse or neglect, foster care, poverty, separation or divorce of parents, domestic violence, school failure, parental or family mental health or substance abuse issues, natural disasters, military deployment of a family member, and grief accompanying the illness or death of a family member.

Unfortunately, youth and parents may be reluctant to discuss their mental health or substance abuse concerns with their pediatrician because of embarrassment, because they do not understand that their concern may be a mental health issue, or because they do not see the physician as a mental health resource. Pediatricians can address these barriers by posting information about mental health–related topics and events and offering mental health brochures and handouts in the physical practice, and by including mental health content on the practice Web site and in newsletters. They can ensure that all members of the practice respect the privacy of children and families and that their language and attitudes reflect the fact that mental illnesses are treatable, that they are no one's fault, and that they do not define the person (eg, a child has schizophrenia, he or she is not a schizophrenic). Pediatricians can also promote mental health through the choice of topics discussed at each visit, whether providing routine health supervision, acute care, or management of a chronic illness. By integrating mental health care into all contacts with the child and family, the physician and office staff demonstrate the importance of mental health, normalize the process of providing mental health care in the medical home, and help to reduce the stigma of mental illness.

PREVENTIVE MENTAL HEALTH CARE AT ROUTINE HEALTH SUPERVISION VISITS

The TFOMH describes a process for incorporating preventive mental health services into routine well-child visits. This process is summarized in an excerpt from the TFOMH Algorithm A (Figure 34-1).

A1a. Visit (prenatal, nursery, or primary care) scheduled.

Scheduling of any visit at any age can trigger data-gathering in advance of the visit, as described in step A2a.

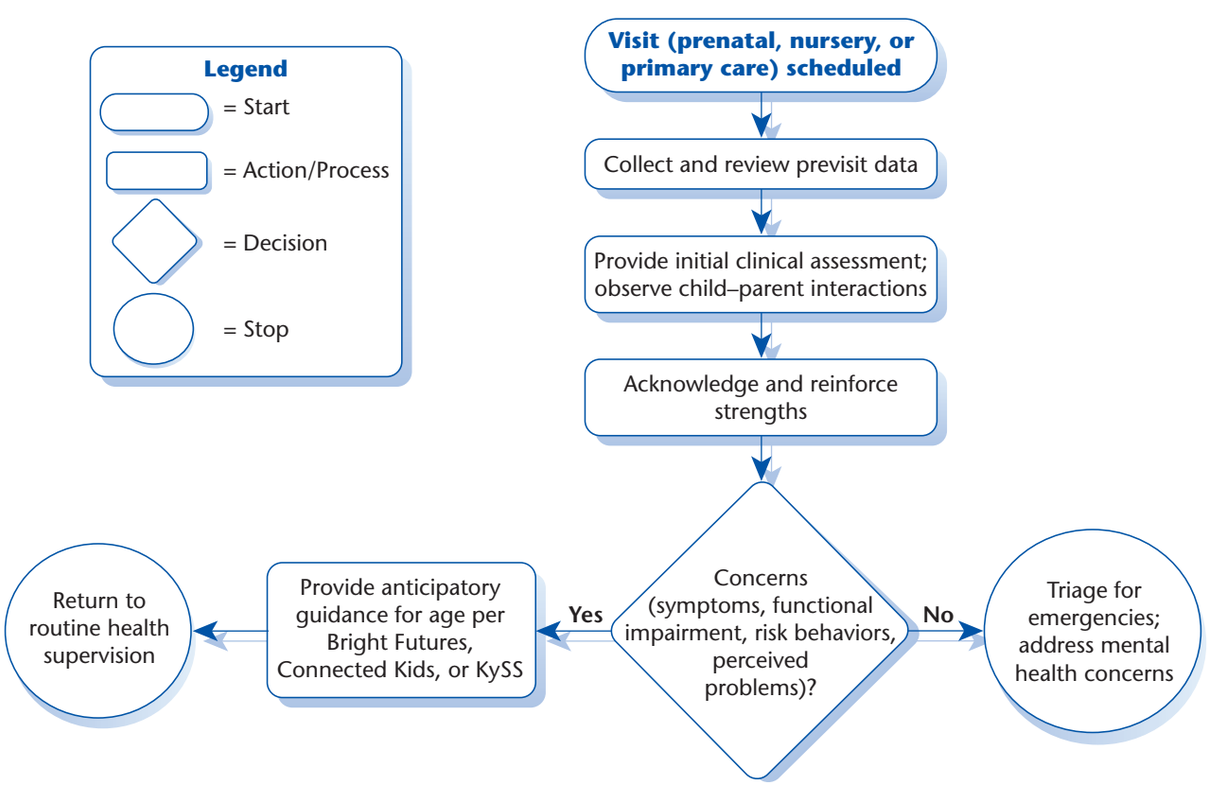
Legend
= Start
= Action/Process
= Decision
= Stop
Visit (prenatal, nursery, or primary care) scheduled
Collect and review previsit data
Provide initial clinical assessment; observe child–parent interactions
Acknowledge and reinforce strengths
Concerns (symptoms, functional impairment, risk behaviors, perceived problems)?
Yes
No
Provide anticipatory guidance for age per Bright Futures, Connected Kids, or KySS
Return to routine health supervision
Triage for emergencies; address mental health concerns

Figure 34-1 Promoting Social-Emotional Health, Identifying Mental Health and Substance Concerns, Engaging the Family, and Providing Early Intervention in Primary Care.

A2a. Collect and review pre-visit data.
To create efficiency during scheduled visits, pediatricians can adopt the use of a pre-visit questionnaire, either paper or electronic, filled out at home or in the waiting room. Such an approach enables the physician to focus on building rapport and on exploring findings, rather than on rote data-gathering, while still being systematic in obtaining information. *Bright Futures Tool and Resource Kit* includes pre-visit questionnaires to elicit a psychosocial history and concerns of parents, and information about changes that have occurred in the family and home, particularly family and environmental stressors. *Bright Futures* also recommends incorporating mental health and substance abuse questions into the adolescent pre-visit questionnaire.

Validated screening tools may be part of pre-visit data collection. Table 34-1 lists a number of those available for use in primary care. Studies demonstrate the feasibility of using brief, psychometrically sound mental health screening tools in the primary care setting. American Academy of Pediatrics recommendations address the type and timing of tools to screen for developmental delays, autism, and behavioral and emotional problems during early childhood. The *AAP Periodicity Schedule* now includes the recommendation to screen all adolescents for depression at health supervision visits. The TFOMH also makes a strong case for periodic mental health screening of children and their families. This includes instruments to assess psychosocial functioning (at home, with peers, at childcare, at school, and in the community) and instruments to identify symptoms associated with mental health disorders. A number of these instruments include parent, teacher, and youth reporting formats. Electronic tools have the advantage of greater acceptability to adolescents. Furthermore, electronic questionnaires provide an opportunity for the use of "item responses." For example, the computer asks the respondent 2 or 3 basic questions. If the answer is "no" to those, the respondent moves on; if the answer is "yes," the computer asks more questions.

Box 34-2 summarizes AAP guidance on psychosocial screening of the child, and Box 34-3 of the family, as published by the TFOMH in June 2010 and affirmed in February 2015 in the clinical report *Promoting Optimal Development: Screening for Behavioral and Emotional Problems*.

Examples of screening tools useful in primary care settings are included in Table 34-1. The use of screening tools does not replace the clinical interview needed to confirm findings and expand on identified problems.

Pediatricians may encounter some limitations to the use of screening tools, including their use in populations for which English is a second language and those for which the cultural context of a child's behavior or family's parenting may vary from that of the population in which the screening tool was validated.

Whatever questionnaires and screening instruments are used, a structured process, developed by the practice in advance, should ensure that the following content is covered:

- Family's priorities for the visit
- Family/social history (including stresses, support system, environmental risk assessment, trauma, separation, and loss)
- Identification of the child's and family's strengths
- Functional assessment of the child and family
- Temperament and risk behaviors
- School or child care reports, if school or child care personnel have expressed concerns
- Symptoms of psychosocial problems

If pre-visit data collection is not feasible, the pediatrician will need to incorporate data collection into the clinical encounter, step A3a.

A3a. Provide initial clinical assessment; observe child–parent interactions.
During the face-to-face encounter, the PCP can complete the following steps:

- Identify, elicit, or review the child's and family's priorities for the visit.
- Review pre-visit questionnaire, screening tools, and other data collected (or complete data collection as described in A2a), review progress on any previous concerns, and update information about adjustment and progress in child care, preschool, or school.
- Broaden the agenda by indicating openness to mental health issues. For example, elicit further information about any current concerns, the child's or family's past or current sources of care for the concerns, and progress on previous concerns; if screening tools have been completed, use any positive responses as a springboard to further discussion and clarification. Ask broad, open-ended questions such as, "What has been the hardest part about taking care of Jonah?," followed by, "What has been the best part?" Such questions convey the doctor's interest in family functioning and invite vexing questions that may have been posed to relatives and friends but may have not felt appropriate for this medical setting. Whatever methods are used to gather information, include inquiry about parental well-being (looking particularly for problems with parental mood, affect, or attachment to the child) and the child's developmentally-specific symptoms of emotional disturbance. Also consider the family's cultural context.
- Observe parent–child interaction. Pediatricians can gain additional insights from examining their own reaction to the parent and child.
- Interact with the child.
- Complete the interview and physical examination (including vision and hearing screen, because a sensory deficit may cause academic or behavioral difficulties).

The increasing independence of adolescents—and the likelihood that parents and guardians may not be fully aware of their adolescents' activities or feelings—reinforce the need for private, confidential discussions between pediatricians and their adolescent patients. These discussions should augment, not replace, discussions with parents. Youth and parents differ in their ability to report on various mental health

Table 34-1 Behavioral and Emotional Screening Measures for Use in Primary Care in the Public Domain[a]

Young children (0–5 yr)	Baby Pediatric Symptom Checklist	2–17 mo	12	Parent completed	Retest reliability and internal reliability >0.7	sites.google.com/site/swycscreen
	Preschool Pediatric Symptom Checklist	18–60 mo	18	Parent completed		sites.google.com/site/swycscreen
	Strengths and Difficulties Questionnaire	3–17 yr	25 items	Parent/teacher 3(4)-yr-old; parent/teacher 4–10-yr-old; parent/teacher follow-up forms available	Variable across cultural groups; sensitivity: 63%–94%, specificity: 88%–96%; available in >70 languages	www.sdqinfo.org
School-age and adolescent children	Strengths and Difficulties Questionnaire	3–17 yr	25 items	Parent/teacher 4–10-yr-old; parent/teacher 11–17-yr-old; youth self-report 11–17-yr-old; parent/teacher/self follow-up forms available	Variable across cultural groups; sensitivity: 63%–94%, specificity: 88%–96%; available in >70 languages	www.sdqinfo.org
	Pediatric Symptom Checklist—17	4–16 yr	17 items	Parent completed; youth self-report >10 yr; pictorial version available	Variable psychometrics for detection of psychiatric problems; available in multiple languages	www.massgeneral.org/psychiatry/services/psc_home.aspx
	Pediatric Symptom Checklist—35	4–16 yr	35 items	Parent completed; youth self-report >10 yr; pictorial version available	Sensitivity: 80%–95%, specificity: 68%–100%; available in multiple languages	www.massgeneral.org/psychiatry/services/psc_home.aspx
PSYCHOSOCIAL SCREENS						
	WE-CARE (Well-Child Care Visit, Evaluation, Community Resources, Advocacy, Referral, Education)	Parent	10 items	Parent completed		pediatrics.aappublications.org/content/120/3/547
	Family Psychosocial Screen	Parent	50 items	Parent completed	Variable psychometrics for detection of specific psychosocial problems; cut points for various domains recommended	depts.washington.edu/dbpeds/Screening%20Tools/FamPsychoSocQaire.pdf

Table 34-1 Behavioral and Emotional Screening Measures for Use in Primary Care in the Public Domain[a]—cont'd

	Survey of Wellbeing in Young Children	Parent	9 items	Parent completed	Preliminary findings show promise	sites.google.com/site/swycscreen/parts-of-the-swyc/family-questions
	Adverse Childhood Experience Score	Parent	10 items	Parent completed	Increasing score associated with many adverse physical and mental health outcomes	acestoohigh.com/got-your-ace-score
SCREENS FOR SPECIFIC DISORDERS						
Parental or adolescent depression	Edinburgh Maternal Depression	Parent (mother)	10 items	Parent self-report	Sensitivity 86%; specificity 78%	www.fresno.ucsf.edu/pediatrics/downloads/edinburghscale.pdf
	2 Question Screen (modification of the Patient Health Questionnaire—2	Parent, adolescent	2 items	Parent or adolescent self-report	Sensitivity: 83%–87%; specificity: 78%–92%	www.cqaimh.org/pdf/tool_phq2.pdf
	Patient Health Questionnaire (PHQ)—9	Parent	9 items	Parent or adolescent self-report	Sensitivity: 88% for major depression; specificity: 88% for major depression	www.integration.samhsa.gov/images/res/PHQ%20-%20Questions.pdf
	Center for Epidemiologic Studies Depression Scale	Parent; adolescents >14 yr (modified version for children as young as 6 available)	20 items	Parent completed; youth self-report	Coefficient $\alpha > .9$; sensitivity: 91%; specificity: 81%. Psychometrics for children <14 indicate measure may not discriminate well between depressed and nondepressed youth	cesd-r.com
	Mood and Feelings Questionnaire	Has been used with children as young as 7	Short version: 9 items; long version: 34 items	Parent completed; youth self-report	Parent report version: sensitivity 75%–86%; specificity 73%–87%	devepi.mc.duke.edu/mfq.html

Continued

Table 34-1 Behavioral and Emotional Screening Measures for Use in Primary Care in the Public Domain[a]—cont'd

Substance abuse	CRAFFT (Car, Relax, Alone, Forget, Friends, Trouble)	11–21 yr	3 screener questions, then 6 items	Interview of youth; youth self-report version available	Sensitivity: 76%–93%; specificity: 76% to 94%; available in multiple languages	www.ceasar-boston.org/CRAFFT
	CAGE-AID	Adolescents	4 items	Youth self-report	One or more positive answers is associated with a sensitivity of 79% and specificity of 77%; ≥2 answers, 70% sensitivity and 85% specificity	www.integration.samhsa.gov/images/res/CAGEAID.pdf
Anxiety	Screen for Child Anxiety Related Disorders (SCARED)	≥8 yr	41 items	Parent completed; youth self-report	Coefficient α: .9	www.psychiatry.pitt.edu/research/tools-research/assessment-instruments
	Spence Children's Anxiety Scale (SCAS)	2.5–6.5 yr and 8–12 yr	45 items	Parent completed 2.5–6.5 yr; youth self-report 8–12 yr	High internal consistency and adequate test–retest reliability in adolescents	www.scaswebsite.com
ADHD	Vanderbilt ADHD Diagnostic Rating Scales	4–18 yr	55-items parent scale; 43-items teacher scale	Parent, teacher completed; follow-up forms available	Sensitivity: 80%; specificity: 75%; retest reliability >0.80	www.brightfutures.org/mentalhealth/pdf/professionals/bridges/adhd.pdf
	Strengths and Weaknesses of ADHD Symptoms (SWAN)	6–18 yr	30 items (18-item version available)	Parent, teacher completed		www.attentionpoint.com/x_upload/media/images/swan-description-questions.pdf
	SNAP-IV	6–18 yr	90 items (18-item version available)	Parent, teacher completed	Coefficient α >.90; available in multiple languages	www.myadhd.com/snap-iv-6160-18sampl.html

CAGE-AID, CAGE Questions (Cut Down, Annoyed, Guilty and Eye Opener) adapted to include drug use; Swanson, Nolan and Pelham Questionnaire, Version IV (SNAP-IV).
[a]This list is not meant to be exhaustive but is representative of a range of screening instruments suitable for primary care that are in the public domain. Psychometrics may vary based on the findings of different studies, and there is considerable variability in the strength of psychometric reliability among measures.

BOX 34-2 Guidance on Mental Health Screening of Children and Adolescents in Primary Care Settings

1. Use validated instruments to screen for socioemotional problems in children 0 to 5 years old with abnormal developmental screening test results (typically performed at 9, 18, and 24 or 30 months) or abnormal autism screening test results (typically performed at 18 and 24 months); at any time the pediatrician observes poor growth or attachment or symptoms, such as excessive crying, clinginess, or fearfulness for developmental stage, or regression to earlier behavior; and at any time the family identifies psychosocial concerns.
2. Use validated instruments to screen all school-aged children (ages 5 through adolescence) for symptoms of mental illness and impaired psychosocial functioning at health maintenance visits; at any time of family disruption, poor school performance, reported behavioral difficulties, recurrent somatic complaints, or involvement of a social service or juvenile justice agency; or when the child or family identifies psychosocial concerns.[a]
3. In addition to #2 above, screen all adolescents for substance use (including tobacco) at each health maintenance visit and whenever circumstances such as an injury, car crash, or decrease in school performance suggest the possibility of substance abuse. If adolescent reports using substance(s), assess for extent of use.

[a]The US Preventive Services Task Force recommends screening adolescents (12–18 years old) for major depressive disorder [specifically] when systems are in place to ensure accurate diagnosis, psychotherapy (cognitive-behavioral or interpersonal), and follow-up.

BOX 34-3 Proposed Screening and Surveillance of Family and Social Environment for Risk Factors

1. Obtain a history of trauma exposure and update child's and family's psychosocial history (eg, parental distress or discord, domestic violence, parental substance abuse or mental illness, youth and family social support, grief and loss issues) at each health maintenance visit and as dictated by clinical need.
2. Screen for maternal depression in the child's first year of life and when psychosocial history indicates. The incidence of postpartum maternal depression peaks when infants are between 2 and 6 months of age.

conditions: a parent may have a more accurate picture of the effect of externalizing symptoms (eg, hyperactivity, inattention, oppositionality), while youth may be better able to articulate the toll of internalizing symptoms or conditions (eg, anxiety, depression); or the youth and parents may disagree about the nature or importance of symptoms. As part of these discussions, pediatricians are obliged to address confidentiality and its limits with both adolescents and their parents. (See Chapter 11, Ethical and Legal Issues for the Primary Care Physician.)

A4a. Acknowledge and reinforce strengths.

Effective mental health care requires that pediatricians move from a medical model focused on problems to a more comprehensive view of the child's and family's capacities. There are 8 empirically-determined independent "intelligences": linguistic, logical-mathematical, spatial, bodily-kinesthetic, musical, interpersonal, intrapersonal, and naturalistic. Acknowledging strengths—one or more of these intelligences; talents; qualities such as resilience, generosity, courage, tenacity, goal-orientation, focus; social supports such as strong family bonds, extended family support, or good peer relations; healthy behaviors such as regular exercise/sleep routines, participation in extra-curricular or spiritual/religious activities; or attitudes such as hope, optimism, motivation to seek help—can build rapport, provide groundwork for an intervention plan, and facilitate accomplishment of subsequent steps. Diagnosing strengths may also stimulate the family to provide further opportunities for the child's development of competence, serving as a buffer for the challenges and peer pressures of adolescence and offering alternatives to risky activities.

A5a. Concerns (symptoms, functional impairment, risk behaviors, perceived problems)?

At this point in the algorithm, the pediatrician need not feel pressed to make a diagnosis, but simply to determine whether or not there may be a mental health concern in the child or family. Box 34-4 outlines symptoms of emotional disturbance by age group. Physical symptoms and signs may, in some instances, point to mental health and substance abuse problems. Box 34-5 outlines physical symptoms and signs suggestive of mental health and substance abuse concerns.

No, there are no concerns.

If the child and family show no signs of functional impairment or distress and if no risk behaviors are identified and no mental health concerns are raised by the family, derived from screening, or perceived by the pediatrician, the pediatrician can move to step A6a.

Yes, there are concerns.

Any findings—functional impairment; symptoms concerning to the child, family, or pediatrician; family distress; exposure to trauma or to significant environmental risks, such as a weapon in the home or family member with mental illness; risky behaviors; or perceived problems—necessitate further attention from the pediatrician. Chapter 370, Psychiatric Emergencies: Suicidality, Agitation, Psychosis, and Disaster Exposure, discusses the process of triaging for psychiatric emergencies. Chapter 50, Care of Children With Mental Health Problems, discusses a primary care process for addressing mental health and substance abuse concerns identified at routine health supervision visits.

A6a. Provide anticipatory guidance for age per *Bright Futures, Connected Kids,* or *KySS*: Keep your Children/Yourself Safe and Secure.

Strategies to promote mental health and provide anticipatory guidance appropriate to the child's age are

BOX 34-4 Behavioral or Emotional Symptoms of Mental Health Concerns by Age Group

INFANTS AND YOUNG CHILDREN

- Excessive crying
- Feeding problems or poor weight gain
- Dysregulation (difficulty organizing feelings and emotions, difficulty being soothed or comforted, difficulty falling or staying asleep)
- Irritability
- Excessive clinginess for developmental stage
- Excessive fearfulness for developmental stage
- Poor eye contact or engagement with caregiver

SCHOOL-AGED CHILDREN

- Anger
- Bullying
- Fighting
- Irritability
- Fear of separation
- Fluctuating moods
- Sleep disturbance
- Academic decline
- Sadness
- Isolation

ADOLESCENTS

- Numbness or avoidance of feelings
- Anger
- Fearfulness
- Aggression, fighting, rule- or lawbreaking
- Self-injury
- Poor school attendance; disciplinary problems; suspension or expulsion
- Appetite change, weight loss or gain
- Difficulty sleeping or excessive sleeping
- Exaggerated mood swings
- Academic decline
- Isolation, withdrawal from friends, loss of interest in usual activities
- Substance use, sexual promiscuity, or other risky behaviors

ALL AGE GROUPS

- Chronic, recurrent, or unexplained physical symptoms
- Very disruptive or persistent nightmares
- Regression to earlier behavior
- Change in sleep pattern
- Exacerbation of chronic mental condition

From Appendix S13: symptoms and signs suggestive of mental health and substance abuse concerns. *Pediatrics*. 2010;125(Suppl 3):S193–S194.

BOX 34-5 Physical Symptoms and Signs Suggestive of Mental Health and Substance Abuse Concerns

SLEEP PROBLEMS

- Excessive sleep
- Significant change in sleep pattern
- Difficulty falling or staying asleep
- Nightmares
- Chronic, recurrent, or unexplained physical symptoms
- Abdominal pain
- Joint pain
- Headache
- Fatigue or low energy
- Loss of appetite
- Epigastric pain or gastritis (alcohol use)
- Chest pain or difficulty breathing (panic/anxiety attacks)
- Oligomenorrhea or amenorrhea, especially in women of low weight (anorexia, teen pregnancy)
- Irregular menses (anorexia, bulimia)

NEUROLOGIC SYMPTOMS

- Leg weakness
- Limb paralysis (conversion reaction)
- Pseudoseizures
- Nonphysiologic neurologic symptoms
- Difficulty concentrating, inattention in school
- Irritability, restlessness

PHYSICAL FINDINGS

- Excess weight gain or loss
- Parotid gland enlargement, dental enamel erosion, calluses or erosions on knuckles (purging)
- Cigarette burns, multiple linear cuts or patterns (self-harm, maltreatment)
- Metabolic abnormalities such as hypochloremic metabolic alkalosis, low potassium, or elevated amylase (purging)
- Recurrent injuries (maltreatment, self-harm)
- Isolated systolic hypertension (alcohol use)
- Chronic nasal congestion (cocaine use)
- Chronic red eyes (marijuana use)

OTHER

- Worsening symptoms of previously well-managed chronic illness
- School absences

From Appendix S13: symptoms and signs suggestive of mental health and substance abuse concerns. *Pediatrics*. 2010;125(Suppl 3):S193–S194.

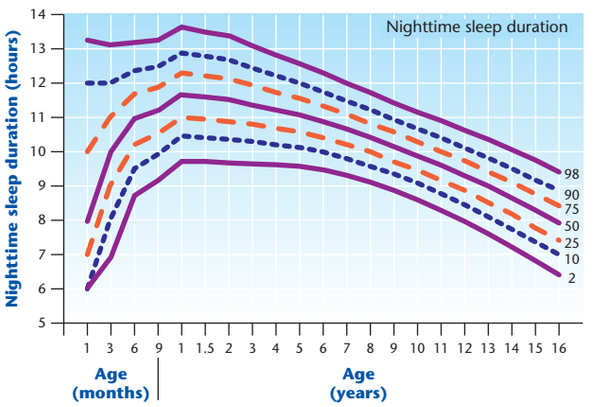

Figure 34-2 Percentiles for nighttime sleep duration per 24 hours from infancy to adolescence. *(From Iglowstein I, Jenni OG, Molinari L, Largo RH. Sleep duration from infancy to adolescence: reference values and generational trends.* Pediatrics. *2003;111(2):302-307.)*

provided in *Bright Futures* 3rd *Edition, Connected Kids, and KySS* (*Keep Your Children/Yourself Safe and Secure*). Mental health is, in fact, one of the core themes identified by *Bright Futures*. Psychosocial topics are a recommended component of every health supervision contact, from the prenatal visit through adolescence. Table 34-2 summarizes mental health anticipatory guidance topics by age.

Several natural strategies for promoting mentally healthy lifestyles have been identified by the AAP Section on Complementary, Holistic, and Integrative Medicine and the TFOMH (toolkit):

- Outdoor time (with appropriate skin protection)
- Special one-on-one time for child with caregiver
- Sufficient sleep (see Figure 34-2 for percentiles of nighttime sleep by age)
- Social connections
- Good nutrition
- Expressions of appreciation and kindness
- Physical activity
- Limited screen time
- Stress management through relaxation techniques

Programs such as *Reach Out and Read* and *Purposeful Parenting* are also helpful for the primary prevention of mental health problems. For a comprehensive listing of resources to promote early brain and child development see www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/EBCD/Pages/Resource-Library.aspx.

PREVENTIVE MENTAL HEALTH CARE AT ACUTE CARE VISITS

Because families sometimes miss routine health supervision visits, and because stress and other mental health issues may be the cause of symptoms presenting as acute problems—eg, fatigue, headache, gastrointestinal symptoms, recurrent somatic complaints—acute care visits present an opportunity to elicit mental health concerns. The TFOMH drew from the expertise of its professional members, opinions of its youth and family members, and informal trials in primary care practices to develop a brief mental health update. (See Table 34-3.)

Responses to these questions provide information that can alert pediatricians to the need for more extensive assessment. In the absence of any concern, 3 to 5 general questions can be completed in a brief time.

Alternatively, pediatricians can use the context of the acute care visit—for example, an injury—to lead naturally into mental health topics—eg, "Had you or your friends been drinking when this happened?", or "Has this person (the perpetrator of the injury) ever threatened you or injured you before?"

Because of the association between sleep difficulties and mental health conditions, questions regarding sleep are helpful throughout childhood. The wording of such questions is important to adolescents, who may have conflict with their parents around sleep issues. The TFOMH recommends that pediatricians avoid questions requiring only yes/no answers and phrasing such as, "Are you getting enough sleep?" Instead they might ask, for example, "How hard is it for you to fall asleep when you want to?"

Adolescents caution that questions on substance abuse and other sensitive topics may seem intrusive and unlikely to yield a candid response during a brief mental health update. A framing statement, such as, "Many young people I'm seeing feel lots of stress this time of year" or ". . . lots of pressure to use drugs . . .," or a circular question, such as "Do any of your friends smoke, drink, or use other drugs?" may be better received than direct questions about the adolescent's behaviors. If the pediatrician has cause for concern, such as deteriorating school performance or injuries, or if this is an issue he or she is already following, more specificity is warranted. Many adolescents do not disclose sensitive information because of confidentiality concerns; therefore, appropriate assurances about conditional confidentiality are a critical part of providing mental health care to adolescents.The Adolescent Health Working Group's *Behavioral Health: An Adolescent Provider Toolkit* provides tools to aid in conversing with adolescents.

If mental health or substance abuse concerns are raised by parents, children, youth, or the pediatrician as a result of a brief mental health update, the process moves on to triaging for emergencies and addressing the concerns. See Chapter 50, Care of Children With Mental Health Problems.

PREVENTIVE MENTAL HEALTH CARE OF CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS

A chronic medical problem or disability places a child or adolescent at greater risk for mental health problems. Unidentified mental health problems in children and youth with special health care needs may contribute to poor adherence to prescribed therapy, somatization, and overutilization of medical services by both

Table 34-2 Anticipatory Guidance by Age

INFANCY (BIRTH TO 11 MONTHS)

MENTAL HEALTH CONCERN	POSSIBLE PROMPTS	ANTICIPATORY GUIDANCE
Poor attachment	[Observe parent-child interactions.] Since the baby was born, have you been feeling down, depressed, irritable, or hopeless? Who is helping/supporting you?	Hold, cuddle, talk to, and sing to your baby often. Respond promptly to your baby's needs. Ask for help from family, friends, and your pediatrician.
Difficult temperament (irritable, hard to console, unpredictable needs, difficulty feeding)	Are you able to comfort and care for your baby? Do you have people to call if you feel frustrated?	Take time for yourself and your partner. Ask for help from family, friends, and your pediatrician.
Child abuse/domestic violence or substance abuse	Do you feel safe in your home? Has your partner ever hurt you or your baby? Have you ever experienced abuse? Have you ever been afraid you might hurt your baby?	Your pediatrician and community resources are available to help your family.

EARLY CHILDHOOD (1–4 YEARS)

MENTAL HEALTH CONCERN	POSSIBLE PROMPTS	ANTICIPATORY GUIDANCE
Delayed development	Do you have any concerns about your child's development, learning, or behavior?	Read to your child often. Enroll your child in preschool or Head Start. Discuss your concerns with your pediatrician.
Poor attachment	Do you have any difficulty understanding or responding to your child's needs? What kinds of activities do you do with your child and as a family?	Be alert for your child's spoken and unspoken messages and feelings; respond promptly to needs. Set aside "special time" one-on-one with your child. Play and eat together as a family. Discuss your concerns with your pediatrician.
Difficulty forming relationships	How comfortable is your child around other people?	Make sure your child has the chance to play with other children. Model kindness to others, taking turns, sharing, and empathy. Discuss your concerns with your pediatrician.
Behavior problem (impulsivity/temper tantrums/aggression)	Do you reward your child for good behavior? What circumstances tend to lead to your child's misbehavior? How do you correct your child for misbehavior? Has your child ever had a very frightening or painful experience or an extended separation from you or another loved one?	Notice and praise your child's good behavior. Do not hit, spank, or yell at your child. Set age-appropriate limits on your child's behavior, and ensure all caregivers use the same rules. Help your child develop vocabulary to describe his or her feelings. Use positive messages whenever possible; eg, "Please use your inside voice" instead of "Don't yell." Consider a parenting class. Encourage healthy habits: good diet, sufficient sleep, physical activity, limited screen time, outdoor play. Discuss your concerns with your pediatrician.

Table 34-2 Anticipatory Guidance by Age—cont'd

MIDDLE CHILDHOOD (5–10 YEARS)

MENTAL HEALTH CONCERN	POSSIBLE PROMPTS	ANTICIPATORY GUIDANCE
Poor success at school, learning difficulties, inattention	How is your child learning and doing in school?	Attend parent–teacher meetings and school events. Limit screen time. Show interest in your child's school experiences and homework. If your child is struggling academically, request testing by the school psychologist. Avoid battles over homework.
Bullying/violence at school	Does your child feel safe and happy at school?	Talk with your child about bullies and bullying. Discuss bullying concerns with school personnel.
Anxiety, worries	How does your child sleep? Does your child have more fears or worries than most children his or her age? Has your child ever had a very frightening or painful experience or an extended separation from you or another loved one?	Talk about what worries your child. Show your child techniques for relaxing. Reward small steps toward managing fears/brave behavior. If your child's worries began after a frightening or painful experience, let your pediatrician know.
Behavior problems (impulsivity/temper tantrums/aggression/oppositionality)	Do you reward your child for good behavior? What circumstances tend to lead to your child's misbehavior? How do you correct your child for misbehavior? Has your child ever had a very frightening or painful experience or an extended separation from you or another loved one?	Notice and praise your child's good behavior. Do not hit, spank, or yell at your child. Set age-appropriate limits on your child's behavior and ensure all caregivers use the same rules. Help your child talk about his or her feelings. Consider a parenting class. Encourage healthy habits: good diet, sufficient sleep, physical activity, limited screen time, outdoor play. Discuss your concerns with your child's teacher and pediatrician.
Depression	Does your child often seem irritable, sad, or depressed?	Help your child talk about his or her feelings. Encourage activities that make your child feel happy, confident, and generous. Encourage healthy habits: good diet, sufficient sleep, physical activity, limited screen time, outdoor play. Discuss your concerns with your pediatrician.

ADOLESCENCE (11–21 YEARS)

MENTAL HEALTH CONCERN	POSSIBLE PROMPTS	ANTICIPATORY GUIDANCE
School problems	How are you doing in school? What do you plan to do after high school?	Praise your child's positive accomplishments in school and involvement in extracurricular activities. Check in with your child's teacher about academic progress and relationships with peers. Attend teacher conferences. If your child is struggling academically, request testing by the school psychologist. Avoid battles over homework. Monitor and limit screen time and use of social media.
Depression/suicide	During the past 2 weeks, how often have you felt down, depressed, irritable, or hopeless? How often have you felt little interest or pleasure in doing things? Have you had trouble falling asleep, staying asleep, or sleeping too much? Have you ever tried to kill yourself or thought about trying to kill yourself?	Listen to your adolescent's hopes and concerns. Encourage activities that make your child feel happy, confident, and generous. Encourage healthy habits: good diet, sleep, physical activity, limited screen time. If you are concerned that your teen is often irritable or depressed, speak to your pediatrician. Be sure your child does not have access to weapons or medications.

Continued

Table 34-2 Anticipatory Guidance by Age—cont'd

ADOLESCENCE (11–21 YEARS)

MENTAL HEALTH CONCERN	POSSIBLE PROMPTS	ANTICIPATORY GUIDANCE
Anxiety	Do you worry a lot or feel overly stressed? How do you sleep?	Set aside time to listen to your teen's hopes and concerns. Encourage healthy habits: good diet, sleep, physical activity, limited screen time. Support your adolescent as he or she figures out healthy ways to relax and deal with stress. Monitor and limit screen time and use of social media.
Substance use or abuse	During the past 12 months, have you drunk any alcohol (more than a few sips), smoked any marijuana or hashish, or used anything else to get high? Have you ever ridden in a car driven by someone (including yourself) who was high or had been using alcohol or drugs? Have you talked with your child about alcohol, drugs, and misuse of medications?	Make sure your child knows how you feel about alcohol and drugs. Know your child's friends and whereabouts. Be a positive role model. Have a safety plan in case your child finds him or herself in a car driven by someone who is high.
Sexual abuse/dating violence	Have you ever felt forced to touch someone or be touched by someone in ways that made you uncomfortable?	Know your child's friends and whereabouts. Model and talk with your child about healthy, respectful relationships.

Table 34-3 Using an Acute Care Visit for a Brief Mental Health Update: Suggested Questions by Age

AGES 0–5 YEARS	AGES 5–12 YEARS	AGES 12–21 YEARS (PARENT/CHILD SEPARATELY)
• How have things been going since our last visit? • How are you coping with [the presenting acute illness]? • How is [the illness] affecting your child, other than primary symptoms? • (If an injury) How did it happen? • How is your child sleeping, in general and in light of the condition? • How are things going at home in general? • Is there anything else that's worrying you about parenting your child?	• How have things been going since our last visit? • How are you coping with [the presenting acute illness]? • How is [the illness] affecting your child, other than primary symptoms? • (If an injury) How did it happen? • How is your child sleeping, in general and in light of the condition? • How is everyone getting along at home? • Has your child been enjoying school? (To the child) How's school going? • What is the best part of parenting this child? What is the most difficult part? • Do you have any worries or concerns about your child's mental health, emotions, or behaviors?	• How have things been going since our last visit? • How are you/how is your child coping with [the acute presenting illness]? • How is [the illness] affecting you/your child, other than primary symptoms? • (If an injury) How did it happen? Had anyone been drinking or using drugs? • How are you/how is your child sleeping, in general and in light of the condition? • How are you/how is your child getting along at home? At school? • [Parents of] teenagers often mention that they are having difficulties with stress, worries, or changes in mood—has this been a problem for you/your child?

Select questions as appropriate to the clinical circumstances and time available.
From American Academy of Pediatrics Task Force on Mental Health algorithm teams, group discussion, fall 2005; and Appendix S8: brief mental health update. *Pediatrics.* 2010;125(Suppl 3):S159–S160.

the child and parents. Efforts to identify mental health concerns are important at each contact with a chronically ill child—especially if the child has experienced frequent emergency department visits or hospitalizations. Parents and siblings may also experience stress and need support, respite, or mental health care. See Chapter 32, Family Support, for resources to address these issues.

SUMMARY

Pediatricians have unique opportunities to promote mental health in children and their families and to identify emerging mental health and substance abuse problems. These opportunities may present themselves in the course of routine health supervision visits, acute care visits, or the monitoring of children with special health care needs. Tools developed by the AAP and other resources may be helpful in implementing a systematic approach to promotion of mental health and early identification of mental health and substance abuse problems.

TOOLS FOR PRACTICE

Community Advocacy and Coordination

- *Connected Kids Clinical Guide* (booklet), American Academy of Pediatrics (www2.aap.org/connectedkids/ClinicalGuide.pdf)
- *Trauma Guide* (Web page), American Academy of Pediatrics (www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/healthy-foster-care-america/Pages/Trauma-Guide.aspx)

Engaging Patient and Family

- *Partnering With Parents: Apps for Raising Happy, Healthy Children* (booklet), Institute for Safe Families (www.instituteforsafefamilies.org/sites/default/files/isfFiles/20130324-Partnering-With-Parents-Brochure-WEB.pdf)
- *The First 1,000 Days: Bright Futures Examples for Promoting EBCD* (booklet), American Academy of Pediatrics (www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/EBCD/Documents/EBCD_Well_Child_Grid.pdf)

Medical Decision Support

- *A Safe Environment for Every Kid* (questionnaire), SEEK Project (www.uspreventiveservicestaskforce.org/Home/GetFileByID/859)
- *Ages & Stages Questionnaires* (assessment) (www.agesandstages.com)
- *Center for Epidemiologic Depression Scale for Children (CES-DC)* (assessment), Bright Futures (www.brightfutures.org/mentalhealth/pdf/professionals/bridges/ces_dc.pdf)
- *Columbia Impairment Scale* (assessment), American Academy of Pediatrics, in *Addressing Mental Health Concerns in Primary Care: A Clinician's Toolkit* (shop.aap.org)
- *Edinburgh Postnatal Depression Scale (EPDS)* (assessment), American Academy of Pediatrics (www2.aap.org/sections/scan/practicingsafety/toolkit_resources/module2/epds.pdf)
- *Feelings Need Checkups Too* (booklet), American Academy of Pediatrics (www.aap.org/en-us/

advocacy-and-policy/aap-health-initiatives/children-and-disasters/Documents/Feelings-Need-Checkups-Toolkit_0823.pdf)
- *Mental Health Screening and Assessment Tools for Primary Care* (chart), American Academy of Pediatrics (www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/Mental-Health/Documents/MH_ScreeningChart.pdf)
- *Modified Checklist for Autism in Toddlers* (assessment), M-CHAT (www.m-chat.org)
- *Patient Health Questionnaire-9 Modified for Teens* (assessment), American Academy of Pediatrics, in *Addressing Mental Health Concerns in Primary Care: A Clinician's Toolkit* (shop.aap.org)
- *Pediatric Intake Form*, Bright Futures (www.brightfutures.org/mentalhealth/pdf/professionals/ped_intake_form.pdf)
- *Pediatric Symptom Checklist* (assessment), Bright Futures (www.brightfutures.org/mentalhealth/pdf/professionals/ped_sympton_chklst.pdf)
- *PEDS Tools* (Web site), Parents' Evaluation of Developmental Status (www.pedstest.com)
- *Strengths & Difficulties Questionnaires* (assessment) (www.sdqinfo.org)
- *The CRAFFT Screening Tool* (assessment), Center for Adolescent Substance Abuse Research (www.ceasar-boston.org/CRAFFT/index.php)
- *The Resilience Project: Clinical Assessment Tools* (Web page), American Academy of Pediatrics (www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/resilience/Pages/Clinical-Assessment-Tools.aspx)

AAP POLICY

Shonkoff JP, Garner AS; American Academy of Pediatrics Committee on Psychosocial Aspects of Child and Family Health, Committee on Early Childhood, Adoption, and Dependent Care, and Section on Developmental and Behavioral Pediatrics. The lifelong effects of early childhood adversity and toxic stress. *Pediatrics*. 2012;129(1):e232–e246 (pediatrics.aappublications.org/content/129/1/e232)

Weitzman C, Wegner L; American Academy of Pediatrics Section on Developmental and Behavioral Pediatrics, Committee on Psychosocial Aspects of Child and Family Health, Council on Early Childhood; Society for Developmental and Behavioral Pediatrics. Promoting optimal development: screening for behavioral and emotional problems. *Pediatrics*. 2015;135(2):384–395 (pediatrics.aappublications.org/content/135/2/384)

SUGGESTED READINGS

Enhancing Pediatric Mental Health Care: Report From the American Academy of Pediatrics Task Force on Mental Health. *Pediatrics*. 2010;125(Suppl 3):S69–S195

Hagan JF, Shaw JS, Duncan PM, eds. *Bright Futures: Guidelines for Health Supervision of Infants, Children, and Adolescents*. 3rd ed. Elk Grove Village, IL: American Academy of Pediatrics; 2008

Kemper KJ. *Mental Health, Naturally: The Family Guide to Holistic Care for a Healthy Mind and Body*. Elk Grove Village, IL: American Academy of Pediatrics; 2010

Shonkoff JP, Phillips DA, eds. *From Neurons to Neighborhoods: The Science of Early Childhood Development*. Washington, DC: National Academies Press; 2000

Chapter 35

HEALTHY WEIGHT

Sandra G. Hassink, MD, MS

Childhood obesity has emerged as a major health problem that increases the risk for chronic illnesses in children. Obesity comorbidities include dyslipidemia, hypertension, type 2 diabetes, nonalcoholic steatohepatitis, gallbladder disease, polycystic ovarian syndrome, slipped capital femoral epiphysis, Blount disease, pseudotumor cerebri, and sleep apnea. These illnesses, along with depression and low self-esteem, are occurring in children with increasing frequency and mandate that obesity prevention, intervention, and treatment become part of the pediatrician's repertoire.

INCIDENCE OF OBESITY

The incidence of obesity has increased dramatically in the United States and the world in the last 2 decades (Figure 35-1). In 2011 to 2012, 34.9% of adults had obesity (defined as a body mass index [BMI] >30), 16.9% of 2- to 19-year-olds had obesity (defined as a BMI >95% for age and gender), and 8.1% of infants and toddlers had obesity (defined as weight/length >95% for age and gender). Obesity prevalence increases with age, affecting 8.4% of 2- to 5-year-olds, 17.7% of 6- to 11-year-olds, and 20.5% of 12- to 19-year-olds. Prevalence of obesity decreased among children 2 to 5 years of age from 13.9% in 2003 to 2004, to 8.4% in 2011 to 2012, which is encouraging, but significant racial disparities persist. In 2011 to 2012, 22.4% Hispanic, 20.2% non-Hispanic black, 14.1% non-Hispanic white, and 8.6% of Asian youth had obesity.

Body mass index (calculated as wt/ht^2) correlates with body fat. This index is used to screen populations for obesity and is the most clinically feasible measure to categorize individuals to target obesity prevention, intervention, and treatment.

In children, body fat changes throughout development, and, therefore, BMI percentile must be used. (See BMI charts in Chapter 16, Pediatric Physical Examination: Interpretation of Findings.) The recommendations of the American Medical Association Expert Committee for children classify BMI between 85% and 94% as overweight and BMI greater than the 95% as obesity (Box 35-1).

Calculation of BMI and classification of weight status at least once a year are considered essential parts of pediatric well care.

EFFECTS OF OBESITY

Increased BMI in adults is correlated with increases in obesity-related comorbidities, and BMI greater than 99% in children is associated with a very high risk of cardiovascular disorders (high blood pressure, elevated insulin, and lipid abnormalities) and severe adult obesity. Obesity is on its way to becoming the largest preventable cause of disease in the United States. It has the potential to make the current generation of US

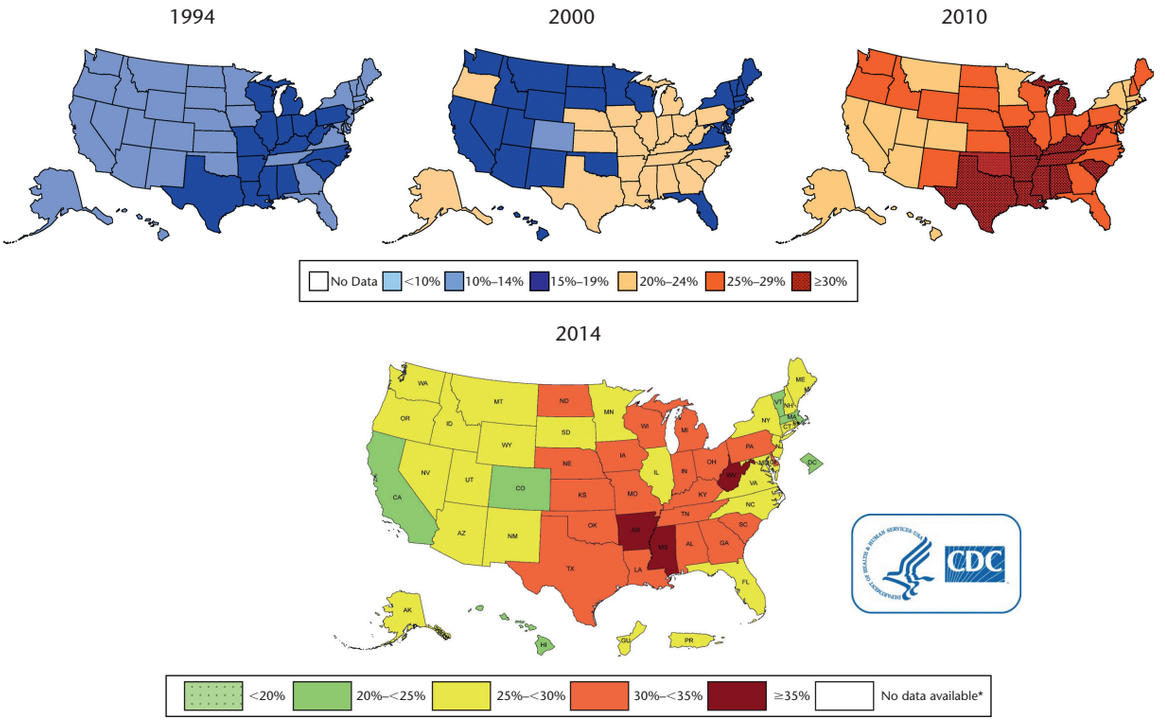

Figure 35-1 Progression of adult obesity in the United States. *(From Maps of diagnosed diabetes and obesity in 1994, 2000, and 2013. Centers for Disease Control and Prevention Web site. January 2, 2015. www.cdc.gov/diabetes/statistics/slides/maps_diabetesobesity94.pdf; Prevalence of self-reported obesity among U.S. adults by race/ethnicity, state, and territory, BRFSS, 2012-2014. Centers for Disease Control and Prevention Web site. September 11, 2015. www.cdc.gov/obesity/data/prevalence-maps.html.)*

BOX 35-1 Classification of Children by Body Mass Index (BMI) Percentage

- BMI <5%: underweight
- BMI 5%–84%: healthy or normal weight
- BMI 85%–95%: overweight
- BMI >95%: obese

children the first to have a shorter life expectancy than their parents.

Pediatricians must be prepared to prevent, identify, and treat obesity and obesity-related comorbidities. These comorbidities include diseases that were traditionally considered adult diseases—sleep apnea, type 2 diabetes, hypertension, dyslipidemia, polycystic ovarian syndrome, and nonalcoholic steatohepatitis. The uniquely pediatric comorbidities of slipped capital femoral epiphysis and Blount disease occur as a result of injury to open growth plates in the hip and knee. Depression and low self-esteem are also associated with childhood obesity. Box 35-2 provides a summary of screening and treatment measures for obesity-related comorbid diseases. Pediatricians also need to be prepared to deal with obesity-related emergencies, such as hyperosmolar hyperglycemia, pseudotumor cerebri, pulmonary emboli, and cardiomyopathy. These comorbidities of obesity add to the burden of chronic disease in children.

Total direct health care costs for children with obesity are estimated to be $14 billion annually, with increased individual costs of $194 for outpatient visits, $114 for prescription drugs, and $25 for emergency department visits. Three billion dollars of this amount is accounted for by children covered by Medicaid.

- Childhood obesity–related hospital costs doubled between 2001 and 2005 to $238 billion.
- A recent study showed that a 10-year-old child with obesity will have an excess lifetime medical cost of $19,000 compared with a normal-weight 10-year-old.

FACTORS ASSOCIATED WITH OBESITY

The cause of the obesity epidemic is multifactorial and complex. Genetic predisposition, the environment, nutrition, and physical activity each play a role in the development of obesity. These factors play out at the individual, family, community, and population levels, accounting for the global shift in obesity demographics.

Genetic Effects

The contribution of genetics to obesity has been studied in twins and shows that BMI is highly correlated

BOX 35-2 Summary of Screening and Treatment Measures

TYPE 2 DIABETES

- *History:* maternal diabetes during pregnancy, small for gestational age, intrauterine growth restriction, family history of diabetes, polycystic ovarian syndrome, obesity.
- *Review of systems:* polyuria; polydipsia, nocturia; recurrent vaginal, bladder, or other infections; recent weight loss. Screen for other obesity related comorbidities.
- *Physical examination:* acanthosis nigricans.
- *Laboratory assessments:* elevated fasting glucose (≥126 mg/dL), positive glucose tolerance test (2-hr glucose ≥200 mg/dL). Hemoglobin A1c (HgbA1c) ≥6.5, symptoms of diabetes plus a random glucose ≥200 mg/dL). Screen for dyslipidemia, nonalcoholic steatohepatitis.
- *Treatment:* tailored nutrition and exercise plan. Metformin. Insulin if severe or uncontrolled on oral medication.
- *Monitoring:* self-monitoring of blood glucose. Follow HgbA1C, lipids and blood pressure, annual screening for nephropathy, retinopathy, and neuropathy.

NONALCOHOLIC STEATOHEPATITIS

- *History:* no specific history; some cases have other family members affected.
- *Review of systems:* possible nausea and right upper quadrant discomfort. Screen for other obesity related comorbidities.
- *Physical examination:* hepatomegaly.
- *Laboratory and imaging assessments:* elevated serum aminotransferases with absence of other causes of liver disease, echogenicity of liver on ultrasound. Screen for diabetes and dyslipidemia.
- *Treatment:* referral to pediatric gastroenterologist for evaluation, definitive diagnosis (liver biopsy), and treatment; weight loss.

HYPERTENSION

- *History:* family history of hypertension or other obesity-related comorbidity.
- *Review of systems:* usually asymptomatic. Screen for other obesity related comorbidities.
- *Physical examination:* elevated systolic or diastolic blood pressure.
- *Laboratory assessments:* evaluation for other causes of hypertension as indicated and for end organ damage; blood urea nitrogen/creatinine, lipids. Screen for diabetes and other obesity related comorbidities.
- *Treatment:* referral to pediatric hypertension specialist, dietary treatment, pharmacologic treatment.

DYSLIPIDEMIA

- *History:* family history of lipid disorders, cardiovascular disease.
- *Review of systems:* asymptomatic; other obesity comorbidities, particularly signs of metabolic syndrome.
- *Physical examination:* no specific signs; acanthosis nigricans may indicate metabolic syndrome.
- *Laboratory assessment:* lipid panel. Screen for other obesity related comorbidities.
- *Treatment:* referral to lipid specialist; dietary management.

SLEEP APNEA

- *History:* family history of sleep apnea.
- *Review of systems:* snoring, snoring with apnea, daytime tiredness, napping, poor concentration in school, enuresis.
- *Physical examination:* large tonsils or adenoids.
- *Imaging assessment:* night-time polysomnography.
- *Treatment:* referral to pediatric pulmonologist, weight loss, continuous positive airway pressure.

SLIPPED CAPITAL FEMORAL EPIPHYSIS

- *History:* knee or hip pain.
- *Review of systems:* knee, thigh, or hip pain, limp.
- *Physical examination:* limp, pain in knee, hip, or thigh.
- *Imaging:* Anteroposterior view of the pelvis and frog leg lateral that includes both hips
- *Treatment:* immediate referral to pediatric orthopedist.

BLOUNT DISEASE

- *History:* bowing.
- *Review of systems:* bowing (tibia vera), knee pain, limp.
- *Physical examination:* bowing, knee pain, limp.
- *Imaging:* Anteropoterior lateral and tunnel view of the knee.
- Treatment: referral to pediatric orthopedist.

DEPRESSION

- *History:* family history of depression, history of abuse, psychological trauma, teasing, low self-esteem.
- *Review of systems:* loss of interest, anger, irritability, sadness, suicidal ideation.
- *Physical examination:* no signs or may have sad, irritable appearance with lack of self-care, flat affect.
- *Laboratory or imaging assessments:* none.
- *Treatment:* mental health referral for counseling or pharmacologic treatment.

From Hassink S, ed. *Pediatric Obesity Prevention, Intervention and Treatment Strategies for Primary Care.* Elk Grove Village, IL: American Academy of Pediatrics; 2007; International Expert Committee. International Expert Committee report on the role of the A1c assay in the diagnosis of diabetes. *Diabetes Care.* 2009; 37(2):1327–1334; and American Diabetes Association. Diagnosis and classification of diabetes mellitus. *Diabetes Care.* 2012;35(Suppl 1):S64–S71.

with genetic factors. Body mass index measures of identical twins reared apart correlate strongly with the BMI of their biological parents rather than their adoptive parents, indicating a strong genetic predisposition toward weight gain. Parental obesity also increases the risk of a child becoming an adult with obesity, allowing for early identification of obesity risk in families.

Newborns of mothers who have obesity or diabetes during pregnancy have an increased risk for childhood and adult obesity, as do newborns who are small or large for gestational age. Maternal gestational weight gain and maternal cigarette smoking have also been implicated in increasing the risk of childhood obesity. The explanation of gene–environment interaction involves epigenetic mechanisms. *Epigenetics* refers to "a set of reversible heritable changes that occur without a change in DNA sequence". The 2 most common epigenetic changes are DNA methylation and histone modification. Studies show that epigenetic changes in monozygotic twins cause increasing genetic divergence over time. Environmental factors can act during intrauterine development, possibly via epigenetic modification of gene expression without altering DNA sequences, to increase the risk of obesity, type 2 diabetes, and cardiovascular disease.

Environmental Effects

Early infant weight gain is independently associated with being overweight in childhood. Infants who gain excess weight in the first 4 months of life are likely to be overweight at the age of 7 years. In addition, the ratio of a child's weight increase between birth and 12 months to birth weight is independently associated with becoming overweight by 6 years of age. When combined with protein intake at 9 to 12 months of age, this early weight gain was able to explain 50% of the variance in boys' BMIs at 6 years.

Prolonged breastfeeding (6 to 12 months) is associated with a reduced risk of becoming overweight among non-Hispanic white children. In an evidence-based review of breastfeeding studies, breastfeeding was associated with a reduced risk of obesity and type 2 diabetes in the children, and type 2 diabetes in mothers.

Minority and disadvantaged children are disproportionately affected by obesity, possibly reflecting a greater exposure to obesity-promoting environments. For example, children from low-income groups, blacks, and Hispanics watch more television than white children. Lower physical activity levels are associated with low family income, time spent indoors, higher crime areas, and maternal education level, factors that differentially affect disadvantaged populations.

Changes in the secular environment have increased calories available to children and families. Portion sizes of commercially available foods began to increase above recommended dietary guidelines in the 1970s and have increased steadily since, with the average chocolate chip cookie more than 700% larger than its counterpart at the onset of the obesity epidemic. Studies in adults and children show that people eat more as portion sizes increase.

Eating out is cited among the factors important in the development of the obesity epidemic. Between 1977 and 1996, the proportion of foods that children consumed from restaurants and fast-food outlets increased by nearly 300%. Fast-food consumption is a significant risk factor for obesity. In one study, children who consumed fast food took in an average of 187 kcal/day more than children who did not consume fast food. In the same study, 30% of children ate fast food on any given day.

Obesity correlates with the number of hours of television viewing. After-school time is a particularly vulnerable time for children in terms of television exposure. Food advertising may play a role in increases in high-energy food consumption. Children are the targets of significant advertising of foods with high caloric density. They see an average of 1 food commercial per 5 minutes of television time and may see 3 hours of food commercials per week. Food advertising ranges from product placement in movies and television shows to vending machines in schools and includes the use of sports heroes to sell soda and highly advertised collectible toys to sell fast-food meals. Exposure to such advertisements affects children's food choices, even in preschool.

Consumption of more than 1 soda per day by children as young as 2 years of age was correlated with obesity. Soda consumption was also associated with excess weight gain in children studied from age 7 years through preadolescence.

Inactivity is also associated with obesity. In a 30-year longitudinal twin study, the twin in the pair who was inactive over the course of the study had significantly more weight gain and waist circumference than the active twin. In a review of obesity prevention trials, moderate to vigorous physical activity was significantly correlated with obesity prevention in children. Nutrition- and activity-related behaviors act at the interface between the individual and family and the environment. The primary care physician can counsel parents and patients on lifestyle issues that affect children's nutrition and activity. Table 35-1 provides age-appropriate obesity prevention information.

Obesity prevention and treatment are family based. Children's eating habits and preferences can be predicted by their mother's behaviors. Maternal preferences predict child preferences for milk type and amount and predict the intake of calcium and cholesterol in the child's diet. Early parental behavior influences a child's eating behavior through at least 5 mechanisms—availability and accessibility of foods, meal structure, adult food modeling, food socialization practices, and food-related parenting styles.

Parental modeling seems to be consistently correlated with child eating behaviors and attitudes. Attempts by parents to control what their children eat or to use food to control other behaviors has much less consistent effects, sometimes having the opposite effect from what is desired. The authoritative parenting style that sets limits in a supportive rather than punitive way is linked with improved health outcomes, including preventing obesity.

Table 35-1 Age-Appropriate Obesity-Prevention Guidance

AGE OF CHILD	NUTRITION INFORMATION	APPROPRIATE ACTIVITY
Newborn or infant	Promote breastfeeding. Teach parents to recognize hunger and satiety cues. Assess family's eating habits and nutrition environment. No juice.	Encourage face-to-face playtime with newborn or infant to lay groundwork for shared activity. Tummy time in a safe, supervised environment. Take daily walk in stroller to establish outdoor time. Use safe toys. No television viewing.
Toddler	Remind parents of appropriate portion sizes. "Parents provide (correct portions), child decides (what to eat)." Encourage structured meals and snack time with family. Model desired eating behavior. Address picky eating, food refusal, and grazing, if problematic. Discuss safe eating to prevent choking. No sugar-sweetened beverages. Limit juice to 4–6 oz/day.	Encourage *free play* in safe indoor and outdoor environments. Spare use of strollers. Limit screen time to <2 hours/day. No screens in the bedroom. Do not mix screen time and eating. Review age-appropriate motor-skill development. Encourage adequate sleep.
Preschool	Parents, not children, should be making food choices. Limit eating out. Review growth charts with goal to *keep on the chart*. Help parents identify and assess all the different nutritional environments in their child's day (ie, child care, school, extended family, friends). No sugar-sweetened beverages or sports drinks. Limit juice to 4–6 oz/day. Be aware of food marketing that targets children. Help parents maintain structured meals and snacks. Help parents address child's behavior around demands for food if a problem.	Encourage free play. Encourage outdoor play. Encourage participation, not competition. Limit screen time to <2 hours/day. No screens in the bedroom. Do not mix screen time and eating. Encourage family time that is physically active. Encourage adequate sleep.
School age	Check nutritional choices at school, after-school care, extracurricular activities; may need to pack food from home. Advocate for change, if necessary. Address weekend, vacation, and summer nutritional challenges. Minimize junk food. No sugared beverages. Limit juice. Lowfat milk and water should be the primary drinks. Nutrition decisions are health decisions. Do not bring food into the house that you do not want your child to eat. Monitor after-school eating.	Balance free play and entry-level sports participation (fundamental skill development with minimal competition and flexible rules). Focus on fun activities. Limit screen time to <2 hours/day. No screens in the bedroom. Do not mix screen time and eating. Help child find other indoor activity options.
Early adolescent	Encourage family meals. Discuss the importance of breakfast (breakfast skipping is common at this age). Help child and family with healthy after-school snack. Help child make decisions around social eating. No sugar-sweetened beverages. Limit juice. Lowfat milk and water should be the primary drinks. Limit eating out and fast food.	Help schedule physical activity around homework and social demands. Encourage extracurricular activities to avoid sedentary time after school. Limit screen time to <2 hours/day. No screens in bedroom. Do not mix eating and screen time. Social-skill building, if needed, can help encourage participation in peer activities.

Table 35-1 Age-Appropriate Obesity-Prevention Guidance—cont'd

AGE OF CHILD	NUTRITION INFORMATION	APPROPRIATE ACTIVITY
Middle adolescent	Review growth chart with adolescent. Help teen with self-assessment of eating and nutritional choices. Encourage breakfast. Discourage meal skipping. Discuss social eating, healthy choices. Limit fast food. No sugared beverages. Limit juice. Lowfat milk and water should be the primary drinks. Limit eating out and fast food.	Find ways to help teen keep participating in physical activity. Encourage lifestyle activities. Limit screen time to <2 hours/day (find alternatives such as volunteering, hobbies, clubs). No screens in the bedroom. Do not mix eating and screen time.
Late adolescent and young adult	Encourage self-monitoring. Discuss structure and time management of meals, activity, and sleep. Go over health priorities. Provide nutrition information on fast food. Screen for binge eating. No sugared beverages.	Maintain activity of daily living. Limit screen time to 2 hours/day. No screens in bedroom. Do not mix eating and screen time. Encourage lifestyle sports and activities. Take advantage of community and school recreation facilities.

Engaging parents and families to partner in obesity prevention and treatment is a core skill for pediatricians. Techniques such as motivational interviewing show promise as feasible office-based interventions. (See Chapter 46, Effective Communication Strategies, for a description of motivational interviewing and other techniques for communicating with children and families.)

OBESITY ASSESSMENT, PREVENTION, AND TREATMENT

The most current methods for preventing childhood obesity are recommended by an expert panel and endorsed by the American Academy of Pediatrics (AAP). The AAP published the *5210 Pediatric Obesity Clinical Decision Support Chart* as a resource for pediatricians.

Assessment

All children 2 years of age and older should have BMI measured at least yearly and have their weight status classified (see Box 35-1). Children younger than 2 years of age should have weight and length measured and weight for length plotted on World Health Organization (WHO) growth charts.

Well Visit

At each well child visit for all children, the physician should

1. Measure height and weight, and calculate and classify BMI, for children 2 years of age and older using the Centers for Disease Control and Prevention growth chart.
2. Plot weight for length for children younger than 2 years of age, using the WHO growth chart.
3. Assess self-efficacy and readiness to change lifestyle behaviors.
4. Assess diet, including attention to the following behaviors that may be targets for change:
   1 Frequency of eating outside the home
   2 Excessive consumption of sweetened beverages, including juice
   3 Consumption of excess portion sizes
   4 Frequency of breakfast
   5 Excessive snack-food consumption
   6 Low fruit and vegetable consumption
   7 Meal frequency and snack patterns and portions
   8 Frequency of family meals
5. Assess activity, including the following:
   1 Environmental support and barriers to physical activity
   2 Whether the child is meeting a recommendation of 60 minutes of moderate exercise every day
   3 Evaluate the child's screen time per day and recommend no screen time for children under 2 years of age and that screen time be limited to 2 hours a day or less in children older than 2 years of age.
   4 Assess location of meals—are meals being consumed in front of a television or computer?
6. Take a focused family history for obesity, type 2 diabetes, liver disease, and cardiovascular disease, including hypertension and early deaths from cardiovascular disease or stroke.
7. Take a pregnancy history for presence of gestational diabetes, obesity, gestational weight gain, and smoking during pregnancy.
8. Assess risk for current or future obesity-related comorbidities.
9. Perform a complete physical examination that includes pulse and blood pressure, as well as signs of obesity-related comorbidities.

10. Order the following laboratory tests:
    1 Lipid profile for all children between 9 and 11 years of age and again between 17 and 21 years of age and all children older than 2 years of age who have a BMI of 85% to 94%.
    2 Every 2 years, aspartate aminotransferase, alanine aminotransferase, fasting glucose or hemoglobin A1c for children with BMI of 85% to 94% with risk factors for obesity-related conditions.
    3 Fasting lipid profile, aspartate aminotransferase, alanine aminotransferase, fasting glucose or hemoglobin A1c, blood urea and nitrogen with creatinine for children with BMI greater than 95% and follow as clinically indicated.
    4 Other studies as clinically indicated.

Prevention of Obesity

For children 2 to 18 years of age with a BMI greater than 5% and less than 84%, the physician should counsel as follows:

- 5 or more servings of fruits and vegetables per day
- 2 or fewer hours of screen time per day, and no television in the room where the child sleeps
- 1 hour or more of daily physical activity
- 0 sugar-sweetened beverages

The physician can also address age-appropriate portion size, structured meals and snacks, and limiting energy-dense snack foods and eating out.

Treatment of Obesity

Children who have a BMI greater than 85% should be treated appropriately. Treatment consists of 4 stages depending on the status of the child and includes all guidance found in the prevention section presented previously and the following points.

Stage 1: Prevention Plus

Stage 1 is also known as *prevention plus*. Messages should build on prevention messages and involve the following areas:

- Establish healthy lifestyle goals with the family using motivational interviewing.
- Focus on evidence-based behavior change.
- Limit consumption of sugar-sweetened beverages.
- Limit television (0 hours before 2 years of age, less than 2 hours for children 2 years of age and older).
- Remove television from primary sleeping area.
- Eat breakfast daily.
- Build on prevention messages in the following areas:
  - Limit eating out.
  - Encourage family meals.
  - Limit portion size.
  - Ensure adequate sleep.
  - May also focus on behaviors where there is suggestive evidence of efficacy.
  - Eat a diet rich in calcium.
  - Eat a diet high in fiber.
  - Eat a diet with balanced macronutrients (food groups).
  - Encourage breastfeeding.
  - Promote moderate to vigorous activity 60 minutes per day.
  - Limit consumption energy-dense foods.

The goal of prevention plus is weight maintenance, and this stage should include monthly follow-up appointments with review of lifestyle goals. If no improvement is seen after 3 to 6 months, then the physician should move to the next stage, as follows.

Stage 2: Structured Weight Management Protocol

In Stage 2, the primary care physician should stress the following areas in addition to developing targeted goals with the family based on evidence as in Stage 1:

1. Develop a plan for a low-energy, dense, balanced macronutrient diet. This may be best done with the help of a dietician.
2. Increase structured daily meals and snacks.
3. Supervise active play at least 60 minutes a day.
4. Limit screen time to less than 1 hour per day.
5. Increase monitoring of these behaviors and encourage parents to follow guidelines as well.

The goal of Stage 2, the structured weight management protocol, is weight maintenance that results in decreasing BMI as height increases. Weight loss is not to exceed 1 pound per month in children 2 to 11 years of age or 2 pounds per week in children older than 11 years of age.

If no improvement is seen in BMI or weight after 3 to 6 months, then the primary care physician should advance to Stage 3.

See the AAP resource *Next Steps: A Practitioner's Guide for Themed Follow-up Visits for Patients to Achieve a Healthy Weight* to target follow up around specific lifestyle goals.

Stage 3

Stage 3 is a multidisciplinary intervention by an obesity care team. If this stage is not successful, then the patient is referred to Stage 4, a tertiary care intervention.

TOOLS FOR PRACTICE

Community Advocacy and Coordination

- *Action for Healthy Kids* (Web site), (www.actionforhealthykids.org)
- *Institute for Healthy Childhood Weight* (Web site), American Academy of Pediatrics (ihcw.aap.org)

Engaging Patient and Family

- *A Parent's Guide to Childhood Obesity: A Road Map to Health* (book), American Academy of Pediatrics (shop.aap.org)
- *About Child & Teen BMI* (fact sheet), Centers for Disease Control and Prevention (www.cdc.gov/healthyweight/assessing/bmi/childrens_bmi/about_childrens_bmi.html)
- *BAM! Body and Mind* (Web site), Centers for Disease Control and Prevention (www.cdc.gov/bam)
- *Encourage Your Child to Be Physically Active* (handout), American Academy of Pediatrics (patiented.solutions.aap.org)

- *Feeding Guide for Children* (chart), American Academy of Pediatrics (www.healthychildren.org/Documents/tables/Feeding-Guide-for-Children.html)
- *Feeding Kids Right Isn't Always Easy: Tips for Preventing Food Hassles* (handout), American Academy of Pediatrics (patiented.solutions.aap.org)
- *Get Fit, Stay Healthy* (handout), American Academy of Pediatrics (patiented.solutions.aap.org)
- *Growing Up Healthy: Fat, Cholesterol and More* (handout), American Academy of Pediatrics (patiented.solutions.aap.org)
- *Choose My Plate* (Web site), US Department of Agriculture (www.choosemyplate.gov)
- *Right From the Start: ABCs of Good Nutrition for Young Children* (handout), American Academy of Pediatrics (patiented.solutions.aap.org)
- *Sports and Your Child* (handout), American Academy of Pediatrics (patiented.solutions.aap.org)
- *What's to Eat? Healthy Foods for Hungry Children* (handout), American Academy of Pediatrics (patiented.solutions.aap.org)
- *VERB: CDC Youth Campaign* (Web site), Centers for Disease Control and Prevention (www.cdc.gov/youthcampaign)

Medical Decision Support

- *Care of Children and Adolescents With Type 1 Diabetes* (policy statement), American Diabetes Association (care.diabetesjournals.org/cgi/content/full/28/1/186)
- *Appendix A.4: Patient Worksheets and Self-assessment Forms*. In: Hassink SG. *Pediatric Obesity: Prevention, Intervention, and Treatment Strategies for Primary Care,* 2nd ed (book), American Academy of Pediatrics (shop.aap.org)
- *Growth Charts* (chart), Centers for Disease Control and Prevention (www.cdc.gov/growthcharts)
- *Obesity Prevention in Pediatrics* (online course), American Academy of Pediatrics (pedialink.aap.org)
- *5210 Pediatric Obesity Clinical Decision Support Chart* (chart), American Academy of Pediatrics (shop.aap.org)

AAP POLICY

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Chapter 36

HEALTHY NUTRITION: INFANTS

Frank R. Greer, MD

Nutrition of the infant is an important topic for the practice of pediatrics. During the first half of the twentieth century, before pediatrics was recognized as a subspecialty, the feeding of infants was an even larger part of the practice of physicians who cared for children, given the high infant mortality rate. The

interaction between the pediatrician and the family over infant nutritional issues helps to establish an ongoing doctor–patient/family relationship that extends into childhood and adolescence. At no other point does the pediatrician have more influence on the nutrition of the pediatric patient. A rapid period of growth and physical development occurs during the first 12 months of life, and with a relatively high level of specific nutrient requirements. It includes the critical period when breast milk or infant formula is the sole source of nutrition, as well as the transition period to a mixed diet that follows the introduction of complementary foods. The nutritional choices made in the first 12 months of life are the basis for future good nutritional practices that are essential for present and future health and well-being. For the best health outcomes, the American Academy of Pediatrics (AAP) recommends exclusive breastfeeding for approximately 6 months followed by continued breastfeeding with complementary foods for at least 1 year and beyond as mutually desired.

OFFICE-BASED HEALTH PROMOTION STRATEGIES

Prenatal Visit

Nutritional guidance for the infant begins ideally with the prenatal office visit, where plans for feeding the infant after birth are discussed with the expectant mother and father. The importance of good maternal nutrition, including folate, prenatal vitamins, and iron for the fetus, is emphasized at this time. If parents are unsure about the benefits of breastfeeding or the mother's ability to breastfeed, this is the ideal time to address these issues and to promote breastfeeding. This would include advice on the initiation of breastfeeding as soon as possible after birth and plans for continuing exclusive breastfeeding for approximately 6 months in accordance with AAP guidelines. If the mother has elected not to breastfeed for any reason, then the pediatrician should also be supportive of this decision and recommend that the infant be placed on an iron-fortified infant formula. The formula choices available can be discussed, as well as the importance of preparing formulas according to the directions on the containers using clean bottles and nipples. Parents should be informed of the availability of supplemental food programs if appropriate, including the Supplemental Nutrition Assistance Program and the availability of the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) food packages for pregnant and lactating women. This is also the time to assess the family for a history of food allergy or sensitivity, to ask about special dietary preferences, including vegetarianism, and to inquire about the maternal intake of medications (including prenatal vitamins) or herbal preparations that may be passed into breast milk. Maternal intake of illicit drugs and alcohol, as well as smoking, should also be determined and discussed as appropriate. If breastfeeding is planned, then the mother should also be assessed for conditions that may make breastfeeding difficult, such as breast reduction or bariatric surgery. Referral to a lactation consultant may be indicated at this time. In recognition of the present pediatric obesity epidemic, parents who are clearly overweight should be identified as at risk for having children who are also overweight. It is not too early for the pediatrician to begin discussing changes in lifestyle that decrease the risk of obesity, including breastfeeding.

Newborn Hospital Visit

Nutritional guidance should be continued at the time of the newborn hospital visit, which should occur within 24 hours of birth. If a prenatal visit did not occur, this visit should include the prenatal nutritional assessment as described earlier, especially if this is a first child and the pediatrician is unfamiliar with this family. If the delivery of the newborn occurs in a planned home birth by a licensed midwife, the newborn should be evaluated within 24 hours by a health care professional experienced in pediatrics.

The hospital visit should include an assessment of infant feeding and an observation of an actual breastfeeding or formula feeding if possible, particularly if this is a first-time mother or a breastfeeding mother who has not been successful with the breastfeeding of previous children. Any newborn or maternal barriers to successful feeding can be assessed at this visit, including complications of labor and delivery and peripartum maternal drug exposure. For concerns about breastfeeding technique, referral to a lactation consultant or other pediatric health care provider is appropriate to ensure a supportive environment for the mother who is breastfeeding. Stool and urine output, as well as degree of jaundice, should be evaluated to identify potential problems with inadequate intake. Newborns initially lose up to 10 percent of their body weight, largely because of fluid loss after birth. How to recognize hunger cues should be discussed, and feeding the infant only when hungry should be emphasized. Expected frequency of breastfeeding is 8 to 12 times in 24 hours in the early days of life, though clustered feeding followed by longer intervals of sleeping often occur. Intake of iron-fortified formula is approximately 20 oz per day after the first few days, which should result in feedings of 2 to 3 oz every 2 to 3 hours. This amount should be increased as the newborn's appetite increases.

The importance of the newborn metabolic screen can be discussed: if positive, this screen may lead to identification of medical disorders that can significantly affect infant nutrition choices as well. In accordance with AAP guidelines, mothers who are breastfeeding should be encouraged to start supplements of 400 IU per day of vitamin D to their infants within the first few days of life. Otherwise, infant formula (as required by federal laws) as well as breast milk contain all the basic nutrients for the sole means of nutritional support for the infant. No additional juice or water is needed.

First Office Visit, 3 to 5 Days of Age (or 2–3 Days After Hospital Discharge)

Careful nutritional assessment is needed in the first week of life, especially if breastfeeding is not well established prior to hospital discharge. The AAP

recommends that newborns discharged at 48 hours of age be seen at a follow-up visit 3 to 5 days after birth, or 48 to 72 hours after hospital discharge. The assessment at this time includes measurements of weight, length, and head circumference that are plotted on the 2006 World Health Organization (WHO) growth charts to include anthropometric measurements made at the time of birth. It would also include a plot of weight for length. Newborns should have gained some weight since hospital discharge, but it is unlikely that birth weight will have been regained at this early visit, especially if the newborn is breastfeeding. Most newborns should have regained their birth weight by 7 to 10 days of life. Physical examination includes an assessment of jaundice and overall hydration status with special attention to the exclusively breastfed newborn. Infants should be feeding 8 to 12 times in a 24-hour period and have 5 to 8 wet diapers and 3 to 4 stools per day. Again, no supplements of water or juice are necessary for either breastfed or formula-fed infants. Parents should be reassured that their infant is getting enough breast milk or formula. If there are problems with breastfeeding and questions about adequate milk intake, the pediatrician should observe a feeding and refer to a lactation consultant if necessary. Formula-fed infants should be receiving iron-fortified formula. Breastfed infants should be receiving an oral supplement of 400 IU of vitamin D each day at this time. Parents should be encouraged not to introduce solid foods before about age 6 months. A discussion of the recognition of the infant's hunger cues as well as the potential for overfeeding of formula-fed infants should be discussed.

Well Baby Visits, 1 to 4 Months

For the 1-, 2- and 4-month well baby visits, anthropometric measurements are again made and plotted on appropriate growth curves with documentation that the infant is growing appropriately for weight, length, and head circumference. Babies should gain about one-half pound per week (1 oz/day) or 2 lbs per month. Breastfed infants will grow more rapidly during the first 6 months of life, but then slow down in the second 6 months of life compared to the more rapid growth of formula-fed infants during this later time period. This information can be used to assure parents that their infant is getting an adequate intake of nutrients. Exclusive breastfeeding (with a vitamin D supplement of 400 IU day) or iron-fortified formula feeding should be continued without water or juice supplements. If the mother is returning to work, then plans for continuing or discontinuing breastfeeding should be discussed, along with options for breast pumps, breast milk storage, or introduction of bottle feeding. Mothers should be asked about conditions in the workplace that support breastfeeding, as present federal regulations require provision of a satisfactory place as well as break time for expressing breast milk. Formula intake should increase from 24 oz at 1 month of age to 30 to 32 oz by 4 months of age. Breastfed infants continue to need 8 to 12 feedings per 24 hours. Growth spurts may occur during this period, which may result in the baby's breastfeeding more often at times. Most infants will double their birth weight between 4 and 5 months of age. Infants will gain approximately one inch per month in length during this period.

The AAP and the Centers for Disease Control and Prevention (CDC) have recommended use of the 2006 WHO growth charts for all US children between 0 and 23 months of age. These can be downloaded readily from the CDC Web site (www.cdc.gov/growthcharts/who_charts.htm). These charts are based on 882 infants who were exclusively or predominantly breastfed for at least 4 months and who continued breastfeeding for at least 12 months. Complementary foods were introduced between the ages of 3 and 6 months. Cohorts of infants and children were from the United States (Davis, CA), Brazil, Norway, India, Oman, and Ghana. Each infant was weighed and measured 21 times in 24 months. Thus, the charts show how predominantly breastfed infants "should grow" under ideal conditions and are considered a "growth standard." This is in contrast to the CDC 2000 curves, which represent a "growth reference," showing how a large cross-section of US infants actually grew between 1970 and the early 1990s, regardless of economic status. These charts used data from infants whose feeding approximated the mix of feedings infants received in the 1970s and 1980s. During this period, 50% of US infants were ever breastfed, and 33% were at least partially breastfed up to 3 months.

Using the WHO charts in an office setting will require a different mindset on the part of physicians and parents. It is recommended for the WHO growth charts that the cutoff percentiles of 2.3% and 97.7%, or 2 standard deviations above and below the mean, be used, rather then the customary 5th and 95th percentiles on the CDC 2000 growth curves. In comparing the WHO and the CDC 2000 growth charts, the WHO charts show a somewhat faster initial weight gain in breastfed infants compared to the mixed-fed infants in the CDC 2000 curves during the first 3 months. After this time, the weight gain of breastfed infants in the WHO charts lags behind the growth rate of the infants in the CDC 2000 charts.

For many years, the CDC charts have been thought to over-identify children who are underweight, the prevalence of low weight for age being 7% to 11% of children aged 6 to 23 months. In comparison, the WHO standard shows a prevalence of less than 3% of low weight for age beginning at 6 months. This should lead to fewer infants being referred for expensive workups for inadequate weight for age, and may be reassuring to concerned parents and physicians. On the other hand, infants and children identified as having low weight for age on the WHO charts will be more likely to have a significant deficiency that will require some intervention.

At the present time, most infants (80%) begin complementary foods between 4 and 6 months of age. There is no evidence that earlier introduction of complementary foods helps infants to sleep through the night. Though there may be some advantages to exclusive breastfeeding for 6 months, the well-documented benefits of exclusive breastfeeding have occurred by 4 to 5 months, including decreasing the risks for infection and atopic disease.

The current AAP policy is exclusive breastfeeding for about 6 months. Mothers should be encouraged to partially breastfeed for about 12 months after the introduction of complemenatry foods, or as long as it is mutually convenient for both parties.

Infants vary greatly in their readiness for solid foods. They are developmentally ready when they can sit with support with good head control and begin putting things into their mouth. Introduction of solids should be done slowly with small amounts of pureed food. The typical infant will respond favorably over a short period of time with resolution of tongue thrusting, more coordinated swallowing efforts, and an increasing awareness of and interest in the foods offered. There is little evidence supporting the timing or the order of introduction of any solid food, but a gradual introduction of a variety of foods, flavors, and textures is recommended.

If breastfed infants are exclusively breastfed beyond 4 months of age without the introduction of iron-rich complementary foods, including fortified whole grain cereals, then, according to AAP recommendations, these infants should be supplemented with 1 mg/kg per day of oral iron beginning at 4 months of age. Partially breastfed infants (defined as those taking more than one-half of their daily feedings as human milk) who are also not receiving iron-rich complementary foods should also be supplemented with 1 mg/kg per day of medicinal iron. Breastfed infants should continue with a supplement of 400 IU of vitamin D per day. Iron supplements are generally not needed for infants receiving iron-fortified formula. As complementary foods are added, it is recommended to gradually introduce well-cooked, strained, or pureed meats with iron (eg, lean beef, pork, chicken, turkey), as these offer the best source of bioavailable iron. For families with vegetarian preferences who are not using iron-fortified formulas, supplements of medicinal iron should be provided for infants.

Well Baby Visits, 6 to 12 Months

Between 6 and 12 months, the pediatrician should continue to monitor the anthropometric measures of growth as described previously. Growth slows down during this period, and infants will regulate their energy intake according to their needs. Infants of this age typically need about 850 calories per day. Most infants will triple their birth weight before 12 months and will grow about one-half inch in length each month. Breastfeeding or formula feeding should be continued. Cow milk, low-iron formulas, reduced-fat milk, goat milk, and soy drinks should not be used at any time during the first year of life. Breastfed infants should continue to receive a vitamin D supplement of 400 IU per day and medicinal iron if the intake of iron-rich complementary foods is limited. Unless a vegetarian diet is a family preference, there are no indications for soy formula. An increasing variety of complementary foods will become a larger part of the infant's diet as the first year of life progresses. At 12 months of age, switching to whole milk is recommended for formula-fed infants, but breastfeeding may continue for as long as is mutually convenient. "Follow-up" formulas are not recommended. However, if the infant is overweight or at risk for overweight, reduced-fat (2% or 1%) milk may be used. Skim milk should not be used. Also at 12 months of age, babies should be screened for both iron deficiency and iron-deficiency anemia. This includes a hemoglobin determination and additional laboratory tests according to the child's risk factors for iron-deficiency anemia (see the following section).

Cup feeding can be introduced after 6 months of age. Fruit juices should not be introduced before 1 year of age, and should be limited to 4 to 6 oz per day with cup feeding. Sweetened beverages or fruit drinks should not be offered. Families should drink fluoridated water.

At approximately 6 months of age, the infant will typically develop her first tooth and, even as additional teeth erupt, mostly pureed foods should be continued because infants largely gum their food even if they have front teeth. Finger foods can also be introduced after 6 months of age. In general, infants should be offered small amounts of a wide variety of foods with different tastes and textures. It is well documented that repeated attempts at offering the same food may be required before the infant accepts the food. There is no scientific evidence to support the introduction of specific food groups at any defined interval. The ultimate goal is a wide selection of foods from every food group (though not necessarily at every meal) so that the intakes of all essential nutrients can be achieved. Similarly, there is little evidence to support the delayed introduction of "allergic foods," including eggs, fish, and peanut butter, which are a rich source of nutrients. Introducing "allergic foods" while still breastfeeding may be protective against the development of allergy. It is important that parents understand to feed the infant only when hungry with appropriately sized infant portions (no more than a few tablespoons) and to progress toward a schedule that corresponds with family meal times as the second 6 months of life progress. Every authority on the subject concurs that feeding should *never* be forced and meal times should never become a battle zone.

NUTRITIONAL IMPLICATIONS FOR PRACTICE

Given the large number of physician/infant contacts that occur during this period, advice for nutritional practice is summarized in Box 36-1.

Nutritional Questionnaire

Pediatricians can assess dietary intake selectively, asking questions about the infant's nutritional status at office visits. This can include asking parents to fill out a questionnaire before the office visit. Suggested questions can be found in Tool A: Nutrition Questionnaire for Infants found in the AAP publication *Bright Futures: Guidelines for Health Supervision of Infants, Children, and Adolescents*: *Nutrition*.

Growth Curves—WHO

The AAP recommends the new WHO growth curves for infants and children up to 2 years of age. The

BOX 36-1 Synopsis of Nutrition Guidance: First Year of Life

PRENATAL VISIT

Discuss feeding options—breastfeeding vs bottle feeding with iron-fortified formula; promote breastfeeding, identify barriers to breastfeeding, discuss optimal breastfeeding environment; assess maternal health, use of prenatal vitamins, and exposure to drugs, alcohol and tobacco; assess family history for food allergy, food preferences, and risk for obesity.

NEWBORN HOSPITAL VISIT

Assess breastfeeding mechanics, stool and urine output; infant physical examination; encourage infant vitamin D supplement of 400 IU/day; discuss newborn screen.

If the newborn was born by a planned home delivery, this assessment should occur by a pediatrician within 24 hours of birth.

OUTPATIENT VISIT IN FIRST WEEK OF LIFE

Physical examination; anthropometric measurements, using World Health Organization (WHO) growth curves 0 to 2 years; assess breastfeeding adequacy and/or formula intake; continue vitamin D 400 IU/day.

1-MONTH AND 2-MONTH VISITS

Physical examination; anthropometric measurements, using WHO growth curves for 0 to 2 years; assess adequacy of breastfeeding/formula intake; continue vitamin D at 400 IU/day; discourage introduction of complementary foods.

4-MONTH VISIT

Physical examination; anthropometric measurements, using WHO growth curves for 0 to 2 years; assess adequacy of breastfeeding/formula intake; continue vitamin D at 400 IU/day; begin iron supplement (1 mg/kg/day) for exclusively breastfed infants; continue iron-fortified formula for formula-fed infants and discuss use of complementary foods beginning at about 6 months of age; juices should not be offered.

6-MONTH VISIT

Physical examination; anthropometric measurements, using WHO growth curves for 0 to 2 years; assess adequacy of breastfeeding/formula intake; infants should be making progress towards eating complementary foods from all food groups, emphasizng those that are good sources of iron; continue vitamin D at 400 IU/day; if iron intake is inadequate, especially for breastfeeding infants, then supplements of iron should be continued (1 mg/kg/day).

9-MONTH VISIT

Physical examination; anthropometric measurements, using WHO growth curves for 0 to 2 years; assess adequacy of breastfeeding/formula and complementary food intake; continue vitamin D 400 at IU/day; infants should be taking complementary foods from all food groups, and these should contain adequate amounts of iron; if iron intake is inadequate in breastfed infants, then iron supplements should be continued; discourage use of whole milk and continue iron-fortified formula or breast milk.

12-MONTH VISIT

Physical examination; anthropometric measurements, using WHO growth curves for 0 to 2 years; assess adequacy of breastfeeding/formula intake, which should be continued until at least 12 months; continue vitamin D 400 IU/day; babies should be taking complementary foods from all food groups that contain adequate amounts of iron; screen for iron deficiency and iron deficiency anemia—babies may need additional iron if screening for iron deficiency is positive and if iron intake is inadequate in babies breastfeeding beyond 1 year of age; begin whole cow milk for babies receiving formula at this time; 2% milk, but not skim milk, may be used in babies who are overweight at 12 months of age.

WHO growth charts are available in pounds/ounces for weight and inches for length. The charts also include head circumference and weight for length. They can be downloaded from www.cdc.gov/growthcharts/who_charts.htm.

It is recommended that pediatric health care providers use the customary WHO cutoff percentiles, 2.3% and 97.7%, or 2 standard deviations below and above the mean.

During the first 3 months of life, the WHO charts show a somewhat faster weight gain than the CDC 2000 charts, the slower growth rate being in the formula- fed infants of the CDC 2000 charts compared with the breastfed infant cohort used in the WHO charts. However, as the rate of weight gain in breastfed infants slows down after 3 months compared with the mostly formula-fed infants in the CDC charts, use of the WHO charts will identify fewer infants during the first year of life with inadequate weight for age.

TOOLS FOR PRACTICE

Engaging Patient and Family

- *Feeding & Nutrition: Baby* (Web page), American Academy of Pediatrics (www.healthychildren.org/English/ages-stages/baby/feeding-nutrition/Pages/default.aspx)

Medical Decision Support

- *Growth Charts* (Web page), World Health Organization (www.cdc.gov/growthcharts/who_charts.htm)
- *Nutritional Questionnaire for Infants* (questionnaire), American Academy of Pediatrics, in *Bright Futures: Guidelines for Health Supervision of Infants,*

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Chapter 37

HEALTHY NUTRITION: CHILDREN

Frank R. Greer, MD

BACKGROUND

This chapter covers nutritional guidance for a broad age range of children. It includes toddlers (13–35 months), preschoolers (36–60 months) and middle childhood (5–10 years). It also includes what is often referred to as the preadolescent period (9–11 years).

After the period of rapid growth and increased appetite of infancy, both the toddler and the preschool-aged child undergo a relative decrease in the rate of growth. Toddlers gain on average 0.5 pounds (0.23 kg) per month and 0.4 inches (1 cm) of height/length per month. The preschool child gains only 4.4 pounds (2 kg) and 2.75 inches (7 cm) per year. Accompanying this decreasing growth rate is a dramatic decrease in appetite and a decreased interest in food. In the parents' eyes, the child may become a "picky" eater.

School-aged children gain an average of 7 pounds (3–3.5 kg) in weight and 2.5 inches (6–7 cm) in height per year. For both weight and height, growth is not continuous, but occurs with irregular spurts lasting on average about 8 weeks. After increasing 0.8 inches (2 cm) during the second year, head circumference increases only by about 2 additional inches (5 cm) between 3 and 18 years. Myelinization of the CNS is completed by age 10 years.

During middle childhood and the preadolescent years, the percentage of body fat reaches a nadir of 16% in females and 13% in males, before increasing again in preparation for the adolescent growth spurt. This normal increase in body fat is known as the "adiposity rebound" and can be a cause of concern for children and their parents as well.

NUTRITIONAL REQUIREMENTS OF CHILDREN AGED 13 MONTHS TO 11 YEARS

The Dietary Guidelines for Americans are readily available (www.health.gov/dietaryguidelines) for checking the targeted nutrient intakes in children after 2 years of age. An average child's diet will generally meet or even exceed these recommendations if healthy food choices are available, as young children have a unique ability to regulate dietary intake when appropriate food choices are made available. On the other hand, regarding the availability of healthy food choices, children between the ages of 2 and 9 years generally do not consume the recommended number of servings of whole grains (6), fruits (2–3), vegetables (3–5), lean meats (2–3) and dairy products (2–3), according to the 2010 dietary guideline report. Thus, an increasing number of children may not be getting the recommended dietary intakes, particularly of vitamins and minerals.